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ABSTRACT

This work reports upon a 1990 questionnaire survey of 16 Pakistani leaders in the field of mental handicap. Results are compared with those of a similar survey conducted in 1982. Most respondents reported that services in this field have increased both in quantity and quality. Differing views were expressed concerning: ease or difficulty of fundraising; terminology and the level of public awareness of mental handicap and ability to differentiate it from mental illness; involvement with self advocacy and parents' movements; effectiveness of services reaching rural and slum populations; access to published books/journals on mental handicap and special education; level of mutual cooperation between voluntary and government agencies; and issues of skill shortage, of environmental design, of equipment availability and of daily transport. Respondents also varied greatly on whether there is a suitable blend of Western and Pakistani ideas and methods, or excessive domination of foreign ideas. Appendices include summaries of development reports written from 1980 through 1988, a paper on the problems of definition and categorization, a discussion of past and future mental handicap studies, and a proposal for planning for mentally handicapped people. (86 references) (Author/DB)

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MENTAL HANDICAP SERVICES : DEVELOPMENT TRENDS IN PAKISTAN

M. MILES

EC 300946

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MENTAL HANDICAP SERVICES:
DEVELOPMENT TRENDS IN PAKISTAN

Report of a Survey

M. MILES

Contributions from Allah Dad Ansari, Oliver Caleb, Munavver Fatima, Qazi Hamidullah, Muhammad Ishaq, Rafiq Jaffer, Munir Ahmad Kamal, Linda Layfield, Laeeq Mirza, Humphrey Peters, Nuzhat Rahim, Amer Raza, Suraiya Samdani, Khalida Tareen, Afifa Waseem; a member of SCINOSA.

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1991

SUMMARY

MENTAL HANDICAP SERVICES: DEVELOPMENT TRENDS IN PAKISTAN

This work reports and reflects upon a 1990 questionnaire survey among leaders in Pakistan's mental handicap field, comparing results with those of a similar survey conducted in 1982. Most respondents assert that services in this field have increased both in quantity and quality. Reviewing recent years and probable developments, there is a diversity of opinion on the ease or difficulty of fund-raising; terminology and the level of public awareness of mental handicap and ability to differentiate it from mental illness; involvement with self-advocacy and parents' movements; effectiveness of services reaching rural and slum populations; access to published books/journals on mental handicap and special education; level of mutual cooperation between voluntary and government agencies; issues of skill shortage, of environmental design, of equipment availability and of daily transport. Respondents also vary greatly on whether they feel there is a suitable blend of Western and Pakistani ideas and methods, or excessive domination by foreign ideas. Appendices review a decade of development reports and outlines, issues of mental handicap categorisation and previous mental handicap studies in Pakistan. An 'information based' approach to mental handicap service planning is recommended.

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PREFACE & ACKNOWLEDGEMENTS

This Survey Report is a small part of the global efforts to evaluate service progress achieved during the International Decade of Disabled Persons (1983-92). It is intended to present the Report at the Tenth Asian Conference on Mental Retardation, at Karachi in November 1991.

While the Report is solely my own responsibility, both the information and the labour and devotion represented here are the collaborative work of several hundred colleagues in every part of Pakistan. From 1978 to 1990, Christine Miles and I worked with local colleagues at the Mental Health Centre, Peshawar, a rehabilitation resource centre run by the Church of Pakistan and recognised by the Government. We also collaborated with rehabilitation professionals on a provincial and national basis through the Frontier Association for the Mentally Handicapped (FAMH) and in the FAMH/UNICEF Community Rehabilitation Development Project.

In 1980, the FAMH affiliated with the International League of Societies for Persons with Mental Handicap (ILSMH). In later years I served on some ILSMH committees and found myself presenting and advocating Pakistani interests in those and other international forums. During the decade, my understanding of Pakistan's cultures and development relied heavily upon the kind advice and instruction of our colleagues. This was supplemented by correspondence and other surveys and research studies, to facilitate mutual cooperation on the national level and to increase my own grasp of the realities of disability and rehabilitation in this large and complex nation. Our colleagues over the years made us feel more like honorary citizens than guests. Yet in the long run the representation of Pakistan's interests clearly must be undertaken by 'real' citizens of Pakistan. It is therefore a great pleasure to know that the current President of the Asian Federation for the Mentally Retarded is Pakistan's Dr Nusrat Awan, and that other highly capable people are also taking part in mental handicap developments on the international plane.

Contributions to the present report are gratefully acknowledged from the following: Allah Dad Ansari, Oliver Caleb, Munavver Fatima, Qazi Hamidullah, Muhammad Ishaq, Rafiq Jaffer, Munir Ahmad Kamal, L. Layfield, Laeeq Mirza, Humphrey Peters, Nuzhat Rahim, Aamer Raza, Suraiya Samdani, Khalida Tareen, Afifa Waseem; and a member of SCINOSA on behalf of Mr A.S. Muslim. Among many others in Pakistan's rehabilitation field whose advice and information I have valued highly over the years, but who could not for one or other reason take part in this survey, I would like to thank Mahjabeen Agha, Z.A. Ansari, Nusrat Awan M.H. Bhutto, Iftikhar N. Hassan, Meher Hasan, K. Zaki Hasan, Sajeela Aslam Khan, Zubeida Khatoon, Hidayatullah Khan, Irfan Aziz Malik, Sibghat-ur-Rehman, Farhat Rehman, Muhammad Shafique, & Safdar Zaman.

Warm thanks to my successor as Administrator of the Mental Health Centre, Mr Humphrey Peters, for facilitating publication of the present Report; to NOVIB (Netherlands) for financial aid; and to Geert Freyhoff, Rafiq Jaffer and Peter Mittler for comments on the report in draft.

October 1991 M. Miles

4 Princethorpe Rd,
Birmingham B29 5PX, U.K.

1.0 INTRODUCTION

This report may best be introduced by the letter sent in Dec. 1990 to 23 people who are prominent in Pakistan's mental handicap service field:

> "Eight years ago the Mental Health Centre conducted a postal survey among leaders and activists in the Mental Handicap field, concerning plans and priorities in development. A report was circulated, and later published in Formative Years: Bulletin of Child Mental Health. Since then, with Federal Government involvement, there have been many training courses, expatriate advisors, new Federal centres, use of Zakat *[see footnote]* funds, National Institute of Special Education, media coverage, graduate training in special education, publications. There have also been more mutual visits and contacts between centres and organisations involved in this field.
>
> This further survey is therefore being made, among leaders and development workers actively involved, to get a sense of the trends in development in Mental Handicap Services in Pakistan. You are very kindly requested to tick the multiple choice boxes and write in answers as required and mail the form in the envelope provided.
>
> Is it worth filling and returning this questionnaire? Busy professionals get a lot of paper thrown at them, and seldom see any benefit from it! In the present case, I undertake that:
> (a) A report will be compiled and a copy sent to all respondents - thus the more forms are completed, the more we will all benefit from sharing our views. (b) Results and trends will be made known to bodies concerned to help develop mental handicap services, e.g. the ILSMH. (c) A paper will be prepared for publication, giving some sense of development from 1982 to 1991, as a contribution to the Decade of Disabled Persons. (d) Contributors will be acknowledged by name. Specific views will not be attributed, to avoid any possible embarrassment."

The letter was accompanied by a questionnaire proforma, which appears in segments below under RESPONSES, with the totals of responses given in brackets against each question. The proforma shown has the original layout slightly compressed. Beneath almost all the questions, there were originally several ruled lines for "any comment you wish to make". Such lines are shown below only once, to save space. The comments that were written in by some respondents are also given, sometimes in abbreviated form.

Apart from the above-mentioned study (Miles & Auret, 1982), survey-type studies concerned with qualitative and service aspects of the mental handicap, mental health and disability fields have been reported by Currer (1978), Hassan (1979), Miles (1979), Abdullah (1981), Jaffer (1981), Miles (1981a), Miles (1983a), Tareen (1983), Tareen, Bashir and Nasar (1984), Miles (1985a), Mubbasher, Malik, Zar & Wig (1986), Nasir & Ansari (1986), Ahmed (1988), Lari (1988), Akbar (1989), Jaffer & Jaffer (1990) (*see References, p.67-69*). This list is by no means exhaustive. It omits purely medical research and all the many small surveys conducted during field work by students of psychology, social work etc, many of which are accessible only in college libraries, and which tend to be weak on methodology and analysis. A broader discussion of previous mental handicap studies and future issues is given in Appendix III.

Zakat: An Islamic tax on wealth, to be expended on welfare objectives.

In 1978, when the author went to work in Pakistan, there were less than ten formal mental handicap service institutions and organisations in the country. Among Pakistan's 80 million (then) population, at least 320,000 people (i.e. a rate of 4 per 1,000) were mentally handicapped to a degree that would be noticeable and problematic in any family or community. Informal services were provided by their families, comprising at least 1,500,000 people. Up to 1978, very little study had taken place of how mentally handicapped people and their families managed their lives. In 1991 there is still extremely little evidence from this 'informal sector', and none from the much larger number of families where one or more members has a mild degree of mental handicap. Pakistan's population is now 115 million, so the latter group, at the '2% level', amounts to 2,300,000 people, living in families totalling over 12 million people.

2.0 PURPOSE & METHOD

The main purpose of the present study, as stated above, was to get a sense of the trends in development of mental handicap services in Pakistan, and to report this to interested parties. Various surveys by Government and by individuals have tried to count and categorise the present formal services and their personnel, but there has been little or no attempt yet to find out in detail what the services actually provide or to assess their quality. From time to time there is talk of evaluating the standards of service provision, an exercise in which satisfactory criteria are notoriously difficult to discover or to apply objectively. Despite this difficulty, leading professionals and participants in the field invariably do have views on the roads they have travelled, the present 'state of the art' and the directions they think the field is taking. This survey intended to sample those views.

The author, as an agent and participant in mental handicap service development throughout the 1980s, had already published views on most of the topics covered in the survey. It therefore seemed useful to compare these views with those expressed by Pakistani colleagues in different parts of the country, who had also worked for several years in service development. There have been visits and meetings from time to time, but these seldom result in any ordered and thoughtful round-up of the state of play. This is partly because it is only the Government that can afford financially to bring together and accommodate people from each end of Pakistan, and participants are reluctant to voice very much criticism on these occasions.

Surveying and reporting the views of learned colleagues is a method with a venerable history in Muslim educational development in the sub-Continent. Sir Syed Ahmed Khan used it, by means of an essay competition, collating the views of 25 distinguished essayists in his Report of the Members of the Select Committee for the Better Diffusion and Advancement of Learning among Muhammadans of India, Benares, 1872 (cf Hafeez Malik (Ed.) 1989, pp.133-180).

The mailed, self-administered questionnaire used in the present survey largely concerns formal services. It also seeks an estimate of changes in information and attitudes, and in the interface between the formal and informal service sectors. The formal services represent accumulations of professional information (*comprising concepts, knowledge, skills and design*) in particular places. They appear to reach less than 5% of the people needing this information. Meanwhile the informal sector represents an accumulation of practical knowledge and experience. This is seldom formally ordered or tested by external criteria, but it is in daily contact with 99% of those needing information. Information factors are discussed further in Appendix IV.

The 1982 survey was more open-ended than the present one and required respondents to answer two broad questions in some depth. The length and perspicacity of those answers varied considerably. In the present survey, it was felt that more specific points should be covered, while also encouraging expanded comments. One reason for this was that during the past few years both the Government and several private individuals have also circulated questionnaires to heads of institutions, in such numbers as perhaps to strain the goodwill of these usually overburdened respondents.

Very busy people could complete the present multiple choice format in 20 minutes, with some pause for thought, even if they were not inclined to write down any further remarks. It was hoped that 20 minutes would not prove too burdensome a demand, while at the same time those who wished to expand their views should have ample space to do so. *[In fact, 12 out of 16 respondents did write comments at some length, 3 others wrote a few very brief remarks, and 1 respondent wrote nothing.]*

3.0 RESPONDENT DETAILS

Among the 16 respondents, 15 gave their names and 12 are personally known to the author. (In 3 cases, the original addressee was absent or delegated the work to someone else). There were 9 males and 6 females, 1 being unknown. Seven work in non-government special schools only; 6 work in non-government special schools plus some other form of mental handicap service; 2 work in Federal Government special schools, and 1 in a national centre. At least 9 respondents worked in their field throughout the 1980s. At least 7 had experience, or were in a position to be knowledgeable, of developments on a province-wide or national level.

Professional backgrounds could be characterised as Teachers: 3; Doctors: 3 Administrators: 3; Psychologists: 3; Speech Therapist: 1; (Not known: 3). Most respondents in fact work in various roles and capacities. At least three have a mentally handicapped close relative.

Respondents reported on work in the following places: Karachi (4); Lahore (5); Jhelum (1); Islamabad/Rawalpindi (2); Mansehra (1); Mardan (1); Peshawar (2). These places range in population from the small rural town of about 40,000 (Mansehra) through 150,000 (Jhelum, Mardan), 1 million (Peshawar), 1.5 million (Islamabad/Rawalpindi) 3.5 million (Lahore), up to the mega-city of about 12 million (Karachi).

The first response was received early in December 1990, from the diligent hand of Mrs S. Samdani, within a few days of the survey being mailed out (sent by urgent Mail Service, with a stamped, addressed UMS envelope for return of the completed questionnaire). A follow-up letter with duplicate questionnaire was sent in mid December, again by UMS. Ten responses were in hand by the end of December, when the author returned to UK. Others forms were forwarded by the Mental Health Centre staff at intervals. The 15th and 16th responses arrived in May and June 1991 (with apologies), requiring the retabulation of all the data and adjustment of the analysis. However, this effort was considered worthwhile in order to extend the range of views and to achieve a response rate of 16/23, i.e. practically 70%.

4.0 RESPONSES

The survey questionnaire format is reproduced below by sections, with totals of responses filled in place of the respondents ticks. Not all the written-in comments are presented, for reasons of space and pertinence, but the salient points have been given. There were 16 respondents, among 23 approached. Many of the responses below total 16. However, some respondents left blanks or indicated more than one choice, so the total may not be 16 in those questions.

****

Respondent's Name..... (For acknowledgement only)

Main area of Mental Handicap Work

.....

1 > IN THE PAST FIVE YEARS, have the numbers catered for by the Centre/School/Clinic/Service-Provision for Mental Handicap that you have mainly been involved with: *(Please Tick One Only)*

1.1 stayed about the same ____[3]___

1.2 increased ____[13]___

1.3 decreased ____[0]___

Any comment you wish to make .....
..... *[This was repeated under most questions]* .....

Reasons given for increase: *"Started outreach program." "Wide publicity and visible improvement in pupils." "Increase at Federal Government centres due to recent start and build-up to capacity." "Older students not moving on because there are no workshops, so school numbers rise as younger children enter." "Increasing public awareness causing families to seek help." "More families coming from out-of-town locations." "Surge noticeable following any mass media coverage, eg TV program."*

Reason for stable numbers: *"Limitations of funds, manpower, volunteer time."*

****

2 > Do you judge that the QUALITY of the service provided in the mental handicap work you are mainly involved with has changed in the past five years?

2.1 about the same __[5]__
2.2 lower quality __[0]__
2.3 better quality __[11]__

Reasons given for improvements: *"Workshops and courses at the National Institute of Special Education helped." "Increasing experience." "Involvement of expatriate specialist."*

Reason for no improvement: *"Lack of resources."*

****

3) If you were to write an article today for an English-language national newspaper of Pakistan, talking about our field of work, which of the following terms would you use, as the main term to describe the field:

(Tick one or two only)

3.1	Mental Handicap	[6]
3.2	Mental Retardation	[7]
3.3	Mental Deficiency	[1]
3.4	Mental Impairment	[2]
3.5	Learning Disability	[4]
3.6	Special Educational Need	[4]
3.7	Intellectual Impairment	[1]
3.8	Intellectual Disability	[1]
3.9	Intellectual Handicap	[1]
3.10	Other (*specify*): _____	[2]

Responses against 3.10 Other (specify) were two: *"Severe Learning Difficulty." "Developmentally Disabled: (There's less negative connotation with this term)"*

Specific remarks about choice: *3.6 "Has a positive ring and is related to education, nearer normal." 3.1, 3.2 "These terms describe the condition, are more familiar to newspaper readers and are not repulsive in any way." 3.2, 3.5 "At this stage of development we still need to be direct and honest to reach general public." 3.1, 3.9 "Prefer Mental Handicap because people have become familiar with it." 3.3 "Comprehensive enough to cover aim and scope of article."*

General comments (choice also shown): (3.1, 3.2) *"All these terms eventually become labels; it is attitude that counts, not the term."* (3.5) *"Terms need to be defined; none is positively informative about service provision."*

****

4) In the past five years, finding funds to run the work has been:

4.1 easier [2½] 4.2 the same as before [5]

4.3 a little harder [3½] 4.4 much harder [5]

Four respondents commented that it was harder to obtain Government funding. One mentioned aid agencies diverting funds towards Afghan refugees or Eastern Europe.

The [½] scores resulted from the response: *"A little harder from local resources but easier from the agencies abroad."* (In the Tabulated Data below, pp.20-22, fractions have not been shown. Each ticked choice has been totalled as an integer).

****

5) Compared with 5 years ago, AND allowing for inflation of 10-15% per year, do you think that you are receiving more, or the same or less support from the following sources (if you receive none, tick the fourth box):

	a) More	b) Same	c) Less	d) None
5.1 Federal Government	[0	2	6	5]
5.2 Provincial Government	[0	2	5	5]
5.3 Zakat Administration	[1	2	2	8]
5.4 Overseas agencies	[3	0	3	5]
5.5 Regular local fundraising	[2	7	1	2]
5.6 Special events	[0	0	3	7]
5.7 Fees for services	[2	7	1	2]
5.8 Membership subscriptions	[0	5	2	5]
5.9 Other (*specify*)_____	[0	3	0	3]

Responses against 5.9 Other (specify) were three: *"Private donors overseas." "Friends & Relatives." "Special donations."*

Further comments: *"Zakat provided capital towards building a centre." "In terms of real value the Institution is receiving less." "Besides fees our main source has been monthly contributions by a few core members." "Local administration (district council) has been more helpful than Provincial or Federal Governments."*

****

6) Do you believe there is greater public awareness now of what mental handicap is, as compared with 5 years ago ?

	a) Much More	b) A Little More	c) Same	d) Less
6.1 Among educated people	5	9	2	0
6.2 Among "the masses"	3	9	4	0

7) Are people any more able to differentiate between mental handicap and mental illness, compared with 5 years ago?

	a) Much More	b) A Little More	c) Same	d) Less
7.1 Among educated people	2	10	4	0
7.2 Among "the masses"	1	6	8	1

Comments on (6) & (7) were given together. *"There is a little more information in the media." "Parents are more willing to bring their children out to school." "We have reached the stage where greater effort at public awareness could produce tangible results in terms of community involvement on a large scale." "Expectations have risen through greater awareness but services remain very limited." "Media information comes only in English, so only the educated become more aware." "There is a reasonable awakening to the need for timely diagnosis of the symptoms, but it would be some time before the difference is appreciated." "Both educated and the masses have some ideas, but sometimes an illiterate parent knows better than the privileged class." "This is mostly guesswork. I wouldn't bet on it - the masses are such a big, widespread mass."*

****

8) Are you involved with any SELF-ADVOCACY activity, where people with mental handicap speak for themselves and formulate their own views about what services they need or would like?

8.1 Yes__[2]___ 8.2 No__[14]__

9) Do you expect that self-advocates will make a noticeable input to Pakistan's mental handicap services IN THE NEXT FIVE YEARS?

9.1 Yes__[6]__ 9.2 No__[4]__ 9.3 Unsure__[6]__

Comments on (8) & (9) were given together.

Where 8.1 chosen: *"People with mental handicap when relieved of mental pressure are encouraged to speak for the reasons of their abnormal behaviour. Skilled handling will of course greatly help."*

Where 9.1 chosen: *"Don't think people with mental handicap can speak for themselves, but if maximum parents of such people come forward as their spokesmen then we can make noticeable input." "Federal Government plans to make a systematic effort on this."*

Where neither 8.1. nor 9.1 chosen: *"We would like to involve families and have started doing so through Outreach." "Some of our children have been involved in a radio program." "In various meetings and functions, our mentally retarded attend for other people to see, meet and communicate with." "Main reason is lack of funds." "Don't see any indications towards self-advocacy."*

##########

10) Are you involved with any group activities CONTROLLED BY PARENTS & RELATIVES of mentally handicapped people?

10.1 Yes__[10]_____ 10.2 No__[5]___

11) Do you expect that parent/relative -controlled activities will make an increasing input to Pakistan's mental handicap services in the next 5 years?

11.1 Yes__[10]__ 11.2 No_[1]__ 11.3 Unsure__[5]___

Comments on (10) & (11) were given together.

Positive comments: *"Once disabled persons/relatives find a voice of their own there will be increasing input in service planning and implementation." "There is a need to mobilise the role of parents and relatives and help them in organising themselves." "Direct Government action would be difficult, but the Federal services would support this trend." "'Parents Voice' is a good, growing example." "It has been through parents groups in other countries that services for the handicapped have been increased."*

Uncertain comments: *"We are trying our best but progress is slow." "Very difficult to make parents participate regularly." "Maybe - parents trends keep on changing." "It may work e.g. 'Parents Voice' in Karachi." "Parents are posing problems and effort is needed to reorient them." "Regular parents/ teachers meetings sometimes with the presence of the affected children would have a salutory effect."* One respondent ticked no choice but wrote *"Unsure what is meant by 'group activities controlled by parents/relatives'".*

##########

12) *"The vast majority of Pakistan's mentally handicapped people live in rural areas and urban slums. Formal mental handicap services are mostly conducted in urban centres, with clients from middle-class families, and with mild or moderate level of handicap."* Is there anything in this statement that you would disagree with or wish to qualify?

12.1 No__[7]_____ 12.2 Yes (*specify what*) ___[9]___

Comments disagreeing or qualifying: *"Our children are nearly all from poor families. Half the school are severely handicapped." "Centres are in urban areas. Mostly custodial mentally handicapped or trainable are getting training." "Vast majority of mental handicap is moderate or mild." "In rural areas and urban slums, children with moderate/mild retardation don't stand out and are easily absorbed. In existing centres at least 20% severely retardeds are also attending." "Urban services mainly cater for lower/middle classes, but some centres have counselling and home-based programs for rural population." "We have started outreach, for an urban slum population of about 15,000 (89 MR children included)." "Our school has several very poor children, and the majority are quite severely handicapped. In Hunza Valley I saw several handicapped children and young people who seemed well loved and cared for and to be an integral part of the community, helping with daily work tasks". "At least 3 of our 29 kids cannot afford proper food and clothing. Most are poor."*

Comment of agreement: *"There are Federal plans to initiate services for the rural population, but no workable model has been evolved."*

One comment by a knowledgeable doctor was not clearly legible. It appears to be: *"The vast majority do not live in rural areas. Although the incidence of SMR [?severe mental retardation] is relatively higher in urban slums but prevalence rate may not be higher than inner city areas as the infant mortality is higher in the urban slums."*

****

13) Do you think the mental handicap services you are involved with have any effect on the problems of mental handicap in

13.1) Rural areas a) Yes__[5]__ b) No__[9]__ c) Unsure_[2]__
13.2) Katchi abadis# a) Yes__[9½]_ b) No__[5½]_ c) Unsure_[1]__

Comments where 13.1 is 'Yes': *"There are some counselling services and community/information based programs especially for katchi abadis/urban slums and rural areas." "Those who benefit become the source of further reference of cases to our centre, thus the word goes around."*

Comments where 13.2 is 'Yes' but 13.1 is 'No' or 'Unsure': *We serve some children who live in katchi abadis." "We have no outlet in rural areas. Perhaps at a later stage they can be approached through our outreach program." "We get rural applicants, but for reasons of transport we are unable to help on a regular basis, but we encourage visits to our school by parents and kids in the hope that they will learn something." "Yes, because our centre will start a program in this area. No, because we have not yet begun."* (The last respondent ticked both 'Yes' and 'No' to 13.2, which scores ½ each).

Other Comments (both answers 'No'): *"Not so far, but there are schemes to attract children and adults from rural areas in the proposed residential program." "We are trying to have community based rehabilitation in any katchi abadi." "Such a strategy was planned but never got off the ground. We still don't have a vehicle after 10 years."*

katchi abadis = slum towns

****

14) Do you possess, or have regular access to any of the following: (Please tick all relevant boxes).

		a) Have Personal Copy	b) Have Access To (e.g. at place of work)
14.1 Western books on mental handicap:	None (x)	[1	2]
	Up to 10 (y)	[4	5]
	More than 10 (z)	[5	3]
14.2 Urdu version of "Special Education for Mentally Handicapped Pupils"		[7	8]
14.3 Any publication of the ILSMH (International League of Societies for Persons with Mental Handicap)		[3	5]
14.4 Any publication of UNESCO on special education.		[2	6]
14.5 Any local-language advice pamphlets for families.		[4	9]
14.6 Do you regularly receive any journal on mental handicap or special education			
	(x) Produced in Pakistan	[3	6]
	(y) Produced abroad	[1	4]

Any other sort of printed resource material _____

Four respondents mentioned that their centre produced some periodical or other publications, one "in cooperation with UNICEF". Two noted receiving 'Parents Voice' journal, two noted Mental Health Centre publications, one noted NISE publications received at workshops, two noted occasional receipt of items from international agencies such as WHO. One mentioned "British and American developmental checklists."

One respondent commented "I have put together both a school library and a teacher's library for our school. In children's library are Urdu HEAL materials for teachers to use in teaching health. We have copies of Mental Health Centre books in teacher's library."

****

15) Thinking of mental handicap services in Pakistan as a whole, do you see 1990/91 as a time of:

15.1	Rapid advance	___[½]__
15.2	Modest advance	___[8½]__
15.3	Standstill, consolidating previous advances	___[3]__
15.4	Standstill, looking for directions forward	___[3]__
15.5	Stagnation	___[0]__
15.6	Slipping backwards	___[0]__

cont.

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The (½) scores arose from one respondent ticking both 15.1 and 15.2, explaining: "Rapid at our centre, with plans to start an outreach program. Modest at the National level." Another respondent ticked no choice, with the modest comment that she "did not have enough material on national basis".

Comments where 15.2 was chosen: *"Some move in community based rehabilitation has been made in Peshawar, Lahore, Karachi." "Punjab University is starting a master's program in special education." "The new leadership has to be motivated and there are reasonable chances of succeeding." "There is a slowing down of activity in both private and public sectors, after a spurt from 1985-1988. However, this may be partly attributed to the process of consolidation."* Other comments (all choosing 15.4): *"Standstill due to lack of funds." "Low priority in government. maybe some progress in NGO efforts. Unlikely to affect masses. It's much more difficult to teach community members to handle mental as opposed to physical handicap."*

16) Compared with your previous experience, what level of mutual cooperation has there been in the past 3 years,

	a) Better	b) Same	c) Worse	d) None
16.1 between Federal Govt and N.G.O.s	[3	10	1	1]
16.2 between Provincial Govt & NGOs	[2	7	1	4]
16.3 between NGO and NGO	[9	5	0	1]

17) If some (further) cooperative activities were proposed, would you in fact have time to take part?

17.1 Yes__[9]__ 17.2 No__[1]___ 17.3 Maybe__[6]__

Comments on (16) and (17) were given together: *"A national level common platform is needed." "We are very short staffed so cannot release teachers for daytime courses." "There has been some government activity in training. Not sure how NGOs have been involved. Our centre has not benefited in any way." "Would cooperate if informed in advance." "Cooperation depends on limitations of our administrative and organisational structure."*

18) Here are listed some topics of current Western interest and attention in the Mental Handicap field. Kindly indicate whether you think they are, or will be, important topics in Pakistan now and in the next 2 years:

	a) Very Important	b) Of modest Importance	c) Not very Important
18.1 Educating MH people for personal relationships, body awareness and sexual functioning.	[7	6	2]
18.2 Facilities for leisure, sport, arts for mentally handicapped people	[8	7	1]
18.3 Vocational training, job placement	[12	3	0]
18.4 Services for elderly MH people	[7	5	3]
18.5 Residence 'in the community' where MH adults live independently with a minimum of necessary support	[7	4	4]
18.6 Genetic counselling for families, to reduce risk of having impaired child.	[13	2	1]

cont.

18.7 Legal actions to ensure MH people enjoy same constitutional rights as other people	[10	4	2]
18.8 Integrating MH children in ordinary school	[7	7	2]
18.9 Measures for prevention of mental handicap	[13	3	0]

General comments: *"There is a need to form a common platform on the national level to reach an agreed scheme for public and govenrmental support." "They are all important topics but it will be a long time before many professionals realise their importance. Most of these topics concern positive attitudes and cooperation from general public who suffer from lack of information." "I see these areas as of concern to professionals in the field today, but don't expect much change in the next 2 years. However, genetic counselling and integration may become important in 5 years time." "Highly skilled personnel would be needed to ensure the efficacy of the program."*

Specific comments: *"Sex education is difficult to teach in Pakistani culture." "Still many parents do not want to see their normal children with mentally handicapped children." "Very mildly handicapped should be in remedial classes in normal schools, saving places in special schools for children with severe learning difficulties." "Integration in ordinary schools is not possible with the existing educational set-up."*

****

19) Across the whole mental handicap field in Pakistan, in which areas of staff skills do you see the greatest shortages at present?

	a) Serious & Critical Shortage	b) Some Shortage	c) Not Very Significant Shortage
19.1 All-round teaching ability	[7	8	0]
19.2 Vocational/occupational training	[7	8	0]
19.3 Speech/Communication training	[14	1	0]
19.4 School management	[4	7	4]
19.5 Managing behavioural disturbance	[9	4	1]
19.6 Environmental design for MH	[8	5	2]
19.7 Assessment & individual programming	[8	8	0]
19.8 Curriculum development	[3	10	1]
19.9 Centre-based Family Counselling	[8	6	1]
19.10 Community-based Rehabilitation	[11	3	1]

Comments: *"Teaching skills are the basic requirement. Training programs for teachers need to include skills related to all the areas mentioned above as these cannot be different categories of trained personnel." "There has been little coordinaton between various professionals, local communities and Ministries of health, education and social welfare services at a national level. Schemes for family counselling and home-based therapy programs have yet to develop to have serious impact on over-all services for mental handicap." "Due to shortage of teachers (through lack of funds) even well trained teachers find it hard to put new skills into practice with classes of 20 children." "Environmental design issues don't figure, nor does CBR. Since most of the work is centre-based some skills have developed mostly through experience and some through training. This is an area in which I think much more can be achieved, i.e. improving skills of existing centre-based staff." "19.3: serious, but less than critical, shortage."*

****

20) Do you experience significant problems of design in the buildings in which your MH services operate? (*Tick any problems*):

20.1 General Accessibility__[6]___ 20.2 Noise level __[3]___
20.3 Lighting__[3]__ 20.4 Heavy traffic risk nearby__[4]__
20.5 Cooling/Heating problem__[6]__ 20.6 Toilet design__[1]__
20.7 Toilet accessibility__[1]__ 20.8 Lacks flexibility for multipurpose use__[4]__ 20.9 Risky electric wiring__[2]__
20.10 Difficulty in provision of food/drink__[3]___
20.11 Lack of space to carry out different activities with individuals [8]
20.12 Other_____[4]_____

Comments on 20.12 Other: Two complained of lack of play space and equipment. Two complained of lack of classrooms, and one of rooms too small to expand numbers. The latter, however, commented *"A lot more could be achieved even in existing space with more imagination and energy."* There were two reports of recent, problem-free, purpose-designed buildings, one report of the current construction of a new centre, and one complaint of lack of resources to build. Furthermore, *"Federal Government special education centres (46 in number) are mostly functioning in rented buildings not quite suitable for the purpose."*

****

21) Is the MH work you are involved with badly hampered by lack of equipment? 21.1 Badly hampered__[2½]___
21.2 Slightly hampered__[8½]___ 21.3 Not a problem__[5]__

The (½) scores resulted from a respondent who desired a category intermediate between 21.1 and 21.2. Comments where choice was 21.1: *"We don't have enough furniture and most classes have no equipment." "Modern facilities are hardly available to cope with the ever increasing complicated cases."*

Where choice was 21.2: *"Needs may change with time. As staff awareness and skills in using technical equipment increases we would be badly hampered." "Local equipment should be fabricated." "MH work is not mainly hampered by lack of equipment but by the lack of information, resources (manpower) and lack of imagination by professionals."*

****

22) Do you think that dependency on road vehicle transport is, or may become, a serious problem for the MH work you are involved with?

	a) Now	b) In next 3 years
22.1 Serious problem	3	5
22.2 Some problem	5	4
22.3 Not a problem	4	1

Comments where 22.1 was chosen (either 'Now' or 'In next 3 years'): *"The centre is not very accessible and lack of transport has been a major reason for student turnover." "Reasons: lack of vehicles; traffic jams; all children couldn't be brought by transport; fuel; Gulf crisis; road safety measures." "We need a new vehicle but have no funds." "Ever increasing demand for proper transportation and lack of proper communication facilities is bound to have profound effects."*

Other comments: *"We pick up children from far flung areas and depend on road transport. "Parents or the school van give transport to our children. There are a couple of students that need to learn to use public transport."*

****

23) Broadly speaking, most of the current mental handicap activities in Pakistan are based on ideas imported or originating in Western countries. Do you think that there has been sufficient cultural/ conceptual adaptation to suit the local conditions/culture/temperament?

23.1 There is a suitable blend of Western/Pakistani ideas & methods __[6]__

23.2 Activities are mostly dominated by Western ideas/methods, with insufficient cultural/conceptual adaptation __[7]__

23.3 There is a need for more ideas/methods from Western countries to provide a framework for local experience to grow __[5]__

23.4 More input is needed from other, non-Western, countries __[8]__

Comments where 23.1 was chosen (sometimes with an additional choice): *"We must necessarily evolve our own methodology and to some extent we have made headway." "So far no major problem has been encountered in the blending of Pakistani and Western ideas." "More is required from the local resources."*

Where 23.2 was chosen (sometimes with an additional choice): *"The initial pattern of services was dominated by western model. There is now the realisation to shape them according to the local needs. However, no specific progress in this area has been visible." "The general tendency has been to take Western ideas and methods wholesale, on the one hand. On the other extreme the poor methods of child-rearing and teaching in local schools have been transferred to MH centres. Need to avoid both. Will happen when administrators and hands-on teachers work closely together to re-think curriculum, methods etc." "Ideas can be brought from anywhere but to make maximum use of ideas we need to plant the imported seed in our own soil to grow according to our own geography, culture, economy, education, land and people." "This* [choice of 23.2] *does not mean that local ideas and methods are not available. I mention with appreciation some publications* [of the M.H.C.] *advocating methods especially suited to us in the Frontier and we here are benefitting to a great extent from them." "Your materials are excellent".*

One respondent indicated a differentiation between Western ideas and methods. The methods were dominant, but there was a need for more ideas.

****

The following Tabulated Data indicate the choices by each individual respondent. The numbers involved are too small for correlations to be studied for significance. However, it is felt to be a sound principle of reporting, that all the data collected should be included, so that any reader might verify the results, and possibly find some interesting correlations that have escaped the author's attention.

More precise identification of each set of responses and written comments was ruled out for reasons of confidentiality. No doubt many of the respondents would have been willing for their names to be attached to their comments and data, but it is likely that other respondents would have been less forthcoming if confidentiality had not been assured.

5.0 TABULATED DATA

Respondents A to R: *(in no significant order)*

Qun.	A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals.....
1.1		+										+			+		3
1.2	+		+	+	+	+	+	+	+	+	+		+	+		+	13
1.3																	0
2.1	+	+			+							+	+				5
2.2																	0
2.3			+	+		+	+	+	+	+	+			+	+	+	11
3.1	+						+	+	+	+			+				6
3.2	+					+				+		+	+	+		+	7
3.3					+												1
3.4				+								+					2
3.5				+		+			+		+						4
3.6		+	+	+			+										4
3.7				+													1
3.8														+			1
3.9								+									1
3.10							+								+		2
																	29
4.1			+			+			+								3
4.2		+						+			+	+			+		5
4.3	+		+	+	+												4
4.4							+			+			+	+		+	5

	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	a	b	c	a+b+c
5.1	d	d	c	d	b		c	c		c	d	b	c	c	d		0	2	6	8
5.2	b	d	c	b			d	c		d	c	d	c	c	d		0	2	5	7
5.3	b	d	d	b	c		d	a		d	d	d	c	d	d	a	2	2	2	6
5.4	c	c	a	d			d	a		d	a	d		d	c		3	0	3	6
5.5	a	b	d	b			d	b		b	b	b	c	b	a		2	7	1	10
5.6	d	c	d				d	c		c	d	d		d	d		0	0	3	3
5.7	b	a	b	a			d	b		b	c	d	b	b	b		2	7	1	10
5.8	b	d	d	b			d	c		b	d	b	c	b	d		0	5	2	7
5.9			b	b				d			b	d		d			0	3	0	3
																	9	28	23	60

	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	a	b	c	d
6.1	a	b	b	a	c	b	b	a	b	b	b	b	c	a	b	a	5	9	2	0
6.2	b	b	c	a	b	b	b	b	c	b	b	c	c	a	b	a	3	9	4	0
																	8	18	6	0

	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	abcd	a	b	c	d
7.1	b	b	b	a	c	b	b	a	b	b	c	b	c	b	c	b	2	10	4	0
7.2	b	c	c	a	c	b	c	b	c	b	c	c	d	b	c	b	1	6	8	1
																	3	16	12	1

A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals

	A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals
8.1	+				+												2
8.2		+	+	+		+	+	+	+	+	+	+	+	+	+	+	14
9.1	+			+	+	+		+						+			6
9.2		+					+					+	+				4
9.3			+						+	+	+				+	+	5
10.1	+		+		+	+		+	+			+	+	+		+	10
10.2				+			+			+	+				+		5
11.1	+	+			+	+	+		+	+			+	+		+	10
11.2															+		1
11.3			+	+				+			+	+					5
12.1			+		+	+		+					+	+		+	7
12.2	+	+		+			+		+	+	+			+	+		9

	abc	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*abc*	*a*	*b*	*c*
13.1	a	b	a	b	a	b	b	b	b	c	c	b	b	a	b	a	5	9	2
13.2	a	b	ab	a	a	b	b	b	a	a	c	b		a	a	a	[9	6]	1

	a b	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*	*a b*
14.1x					a b					b										
14.1y	a b			b				b			a b	b		a		a				
14.1z		a	b			a b	a		a b								a			
14.2	a b	a	a b	b		a b	a	b	b	b								b	a	
14.3	a b	a	b					b	b	a			b							
14.4	a b	a	b	b		b			b	b										
14.5	b	a	b	b		b		b		b	a b		b	a		b	a			
14.6x	a b		b			b	a		b	b			b							
14.6y	a b	b	b										b	a						

	A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals
15.1			+														1
15.2	+		+	+		+			+		+			+	+	+	9
15.3								+				+	+				3
15.4		+					+			+							3
15.5																	

	abcd	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*abcd*	*a*	*b*	*c*	*d*
16.1	b		b	c	b	a	b	b	b	b	b	b	b	a		d	a	3	10	1	1
16.2	b		c	b	b		d	b		d	d	b	b	b	a		d	a	2	7	1	4
16.3	a	a	a	b	b		d	b	b	a	a	b	a	a	a		a	9	5	0	1
																		14	22	2	6

	A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals
17.1				+	+			+	+		+	+	+	+		+	9
17.2															+		1
17.3	+	+	+			+	+			+							6

	A	B	C	D	E	F	G	H	J	K	L	M	N	P	Q	R	Totals		
	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	a	b	c
18.1	a	c	a		b	a	b	c	b	b	a	b	a	a	b	a	7	6	2
18.2	a	b	a	b	b	a	c	a	a	b	a	b	b	a	b	a	8	7	1
18.3	a	b		a	a	a	a	a	a	a	b	a	b	a	a	a	12	3	0
18.4	a	c	c	a	b	b	a	b	b	c	a	a		a	b	a	7	5	3
18.5	a	c	b	c	a		a	b	b	a	a	c	c	a	b	a	7	4	4
18.6	a	c	a	a	a	a	a	a	a	b	a	b	a	a	a	a	13	2	1
18.7	a	c	a	a	a	a	b	a	a	b	b	c	a	a	b	a	10	4	2
18.8	a	c	b	b	b	b	a	a	a	b	b	c	a	a	b	a	7	7	2
18.9	a	b	a	a	a	a	a	a	a	a	b	a	a	a	b	a	13	3	0
																	84	41	15

	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	abc	a	b	c
19.1	a	b	a	P	a	a	b	a	b	b	b	a	b	b	a	b	7	8	0
19.2	a	a	a	A	b	b	a	a	b	b	b	b	b	a	a	b	7	8	0
19.3	b	a	a	G	a	a	a	a	a	a	a	a	a	a	a	a	14	1	0
19.4	b	b	a	E	c	b	c	b	a	a	b	b	c	a	c	b	4	7	4
19.5	b	a	b		a	a	b	a	a	b	a	c	a	a	a		9	4	1
19.6	a	a	a	W	a	b	c	b	a	c	b	a	b	a	b	a	8	5	2
19.7	b	b	a	A	b	a	b	b	a	a	b	a	b	ab	a	a	8	8	0
19.8	b	b	a	S		b	b	b	a	b	b	a	c	b	b	b	3	10	1
19.9	a	b	b		a	a	a	a	a	b	a	a	c	b	b	b	8	6	1
19.10	a	a	a	N	a	a	b	a	a	b	a	a	c	a	b	a	11	3	1
				O													79	60	10
				T															
20.1	+	+	+						+	+				+			6		
20.2	+			F			+				+						3		
20.3				I					+						+	+	2		
20.4	+			L					+	+	+						4		
20.5	+	+	+	L								+			+	+	5		
20.6			+	E													1		
20.7				D										+			1		
20.8	+	+							+		+						4		
20.9	+			I							+						2		
20.10			+	N					+					+			3		
20.11	+	+	+				+		+	+	+	+					8		
20.12		+	+				+		+								4		

21.1			+		+		+										3		
21.2	+		+	+						+	+	+	+	+		+	9		
21.3		+				+		+	+						+		5		

| | a | b | a | b | a | b

6.0 DISCUSSION

Discussion of the survey will initially review the sources and take up their responses to various associated parts of the questionnaire; and will then consider how far services have developed as compared with earlier reviews:

6.1) METHOD & SOURCES

6.2) CURRENT SITUATION ASSESSMENT

a) General Quantity and Quality .....[Qu.s 1, 2, 15].

b) Skills, Plant, Transport & Equipment ....[Qu.s 19-22].

c) Financial Support & Public Awareness ....[Qu.s 3-7].

d) Self-Advocacy & Parent Involvement .....[Qu.s 8-11].

e) Extent & Relevance of Services .....[Qu.s 12, 13].

f) Information Resources & Mutual Help .....[Qu.s 14, 16, 17].

g) Incoming Trends & the East-West Balance..[Qu.s 18, 23].

6.3) PACE & QUALITY OF DEVELOPMENT.

6.1 METHOD & SOURCES

Due to time constraints, it was not feasible to pre-test the questionnaire, which therefore went out with some possible ambiguities and omissions. The exercise was conducted in English, which seems to be the language preferred by educated Pakistanis for professional discussion, and was a necessity for the author. A few of the written-in comments suggest that not all the respondents were entirely at ease in the vocabulary and concepts with which questions were framed. At least one intended respondent could not manage the English and did not return the questionnaire. Ideally there should be a choice of languages, though it is not clear that there is yet a sufficiently well-developed common professional vocabulary in Urdu to cover all the points raised.

The author confesses to a personal dislike for what respondents were asked to do, i.e. filling a questionnaire. Among the multiple choices offered, there seldom seems to be a choice that reflects exactly one's own viewpoint. Many questions beg to be answered with "It depends what you mean by ...."! The more sophisticated questionnaire asks respondents to choose the answer 'nearest' to their own view, or to score from 0 to 10 their agreement with a given statement. Yet the habit of intellectual life is precisely to differentiate one's views from those that are 'near', and constantly to question what one does really think. It was encouraging that, at various points, respondents questioned or disagreed with the questionnaire and added their own variation, e.g. their own option of 'Don't Know'; or ticked both 'yes' and 'no', giving the different circumstances in which each would be the correct answer.

There is also some danger of framing or ordering questions in such a way as to indicate a 'right' answer. Further, most of the respondents know the author and have read some of his papers, and could perhaps be influenced to choose options in the light of the author's known views - either for or against - rather than purely giving their own opinion. The author was conscious of this while analysing responses, but did not get the impression that these factors played much part. (The danger also exists in a purely anonymous survey, that respondents may give answers that are inaccurate, ironic or mischievous).

In the present survey, the diversity of views was outstanding. However, it was sometimes necessary to read between the lines in order to resolve apparent conflicts. For example, two respondents took totally opposite views in Qu. 18, which lists 'some topics of current Western interest' and asks whether the respondent thinks they are, or soon will be, important topics in Pakistan. One respondent ticked all the topics as 'very important'. The other ticked most of them as 'not very important' and the rest as 'of modest importance'. The author happens to know that these two respondents in fact have a generally similar viewpoint on their field. The explanation lies in their written-in comments. The first stated that he personally thought all the listed topics were very important, but felt it would be a long time before their importance was widely recognised. The second commented that the topics were matters of concern to professionals, but he foresaw little change in the near future.

This question could have been phrased more clearly, to differentiate between topics being 'important' *per se*, and their importance being 'recognised', by professionals or the general public. Yet to phrase the question that clearly would have involved an assertion, from the author's side, of a belief that these topics are important, which could prejudice the responses. To get around this danger would require a more complicated sort of instrument, dividing respondents into groups according to their earlier responses and taking them through a divergent sub-set of questions. This is feasible in live interviews, where the respondent does not know what the alternative sub-sets are, but is difficult in a mailed, self-administered questionnaire. It was also felt that any greater degree of complexity would reduce the number of responses received and would introduce many further inconsistencies of interpretation.

Thus it is both a limitation and a strength of the present survey, that it is not a purely objective exercise of opinion-sampling among a population that is knowledgeable but personally unknown to the investigator. The author knows most of the respondents and their working situations, a knowledge that sheds light on some of their expressed views. The risk then is that analysis of the survey responses might be biased by the author's interpretation. In the 1982 survey, where responses were entirely open-ended, this bias was allowed for. A recently-arrived colleague, Ms Louise Auret, who was familiar with the mental handicap field but not with the Pakistani personnel, did the analysis of those responses. That option was not available for the present survey, so the author can only acknowledge the risk of personal bias and try to counteract it.

If a particular Yes/No question had received 16 'Noes' out of 16 responses (which none of the present questions did), it would still not be possible to say that 'mental handicap professionals in Pakistan reject this proposition'. The sample is too small, and rather few of the interesting issues admit of a straight Yes/No response. A unanimous response would, however, be a useful and interesting indicator. [*The nearest to unanimity in fact were two 14/16, three 13/16, one 12/16, two 11/16, six 10/16, nine 9/16, out of 164 opportunities for 16/16 to occur, though most of these were not simple Yes/No questions*]. There are perhaps between 500 and 1,000 people in Pakistan with some daily professional involvement in mental handicap services (including pediatricians and lawyers), but among these there are not more than perhaps 30 or 40 whose professional mental handicap experience extends beyond their immediate locality and has accumulated over several years, who therefore would be in a position to make an informed contribution to this survey.

6.2 CURRENT SITUATION ASSESSMENT

6.2 (a) Quantity and Quality

A majority (13/16) of respondents reported [Qu.15; pp.15-16] a mildly optimistic overall view of mental handicap services in Pakistan, believing that currently (1990/91) the field was advancing or was consolidating previous progress. (This view would certainly be held by one respondent who modestly declined to give opinions on a nationwide basis). The minority report (3/16) did not deny that there had been progress, but, believing that it had now come to a standstill, was not optimistic for the future. To some extent, so broad aquestion might assess the personal and political viewpoint of the respondent, rather than the factual state-of-the-art of the mental handicap field. Yet even among those who may take a predominantly dyspeptic view of current events in Pakistan, none went so far as to report stagnation or actual regress.

The overall current view is probably influenced by the progress of respondents' own work over the past 5 years. There [Qu.1, 2; p.10], a majority reported increased numbers (13/16) and judged that the quality had improved (11/16), while the remainder saw a steady state. It appears from the Tabulated Data that among the 13 reporting increased numbers served, 10 also judged that their quality had improved, while 3 believed it to have remained stable.

The author's experience, as a manager, advisor or governor of 12 new service centres during the 1980s, was that during the initial phase of development numbers would increase, staff would gain experience, and funding might keep pace, so that there could indeed be an increase of both quality and quantity for several years. Yet after this early growth phase, it was extremely hard both to serve more clients and also to maintain or improve quality, especially as finances became harder to raise. Many centres, in the North West Frontier and elsewhere, were under strong pressure to crowd in more clients without any increase of staff skills or resources, to the detriment of service quality.

Respondents' comments indicate that some of the services, especially the Federal centres, have been in their early growth phase. It remains uncertain whether financing and resource development will be sustained. Clearly, several centres had appreciated the growth of staff experience and skills, aided by NISE courses and expatriate involvement, but the funding position [Qu. 4, 5; pp.11-12] has been less positive. Several centres have increased their clientele by 'outreach' services, a means of doing more with available resources though seldom a means of improving quality.

In a very different phase, at least one centre, over 15 or more years, had filled up with clients from the younger end without being able to move the older clients onwards, while also suffering a decline in resources. It is hard to see how there can be maintenance of quality in such a situation, where *"we are very short staffed, we don't have enough furniture and most classes have no equipment"*. It may be the case that, as long as their service facility were still functioning, no respondent would actually offer the judgement that the quality was declining, even where this was manifest from their other comments.

6.2 (b) Skills, Plant, Equipment & Transport

Almost all the staff skills listed in Qu.19 (p.17) were thought to be in short supply, often critically so. The Government also views a skill shortage as "the biggest constraint, in developing services" (Special Education & Social Welfare Division, 1990, p.16). Skills for Speech & Communication were the ones most prominently thought lacking, followed by those for Community Based Rehabilitation. Lari (1990, p.77) also found that 'Language and Speech' was

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the highest curriculum priority among special school headteachers (65% of whom were running schools for deaf or mentally handicapped students).

The perceived shortages may reflect questions of definition. There are very few specialist speech therapists in Pakistan, yet every competent special teacher carries out some of the basics of speech-language-communication development and therapy. This was recognised in the comment that "*Teaching skills are the basic requirement*", and that teachers should have something of all the skills listed. Similarly, there are very few people specialising in 'Community Based Rehabilitation' (in any of its many meanings), yet the basic skills of counselling, family involvement, home-centre liaison, raising community awareness and support, are already practised by some centres, which act in effect as a focus of resources for community based rehabilitation.

Urban mental handicap services may be at the stage where specialisation occurs and the various emerging specialists compete for scarce resources and erect professional barriers around their 'turf'. This phase may be inevitable, but will not necessarily bring much benefit, in the short or medium term, to people with disabilities or the wider community. In countries that have undergone this development, the phase of specialisation among rehabilitation professions may last from 20 to 100 years before there are moves to break down the segmentation and to collaborate across disciplines. The latter move may coincide and interact with a trend towards demystification of professional procedures and towards a greater participation of 'clients' and families.

A peculiarity of developments in Pakistan is that several phases and trends seem to have arrived almost on top of one another, probably as a result of foreign influences and experience. This is not very widely perceived or understood, so one finds organisations trying simultaneously to develop projects that are mutually incompatible. The management's own instincts may be to acquire staff with more specialist skills and to use them to do much more competently those activities in which the centre is already engaged. Funding agencies, however, may be pressing the centre's or association's management to spread current resources out into the community to reach a far greater number of clients and thus to give a better return for money invested (or at least bigger in number, if not necessarily better in quality).

Thus the skills that were least emphasized by respondents, i.e. school management and curriculum development, may in fact be critically scarce. ('Centre' or 'Organisational' management would have been better terms than 'School' management). Both sets of skills involve the ability to examine current practice, to set targets in the light of changing local and national requirements, and to acquire and deploy/redeploy resources optimally to meet the targets. However, most respondents did not view it this way. There are, of course, problems of definition and consistency in a short survey such as this. To ensure that all respondents had a similar understanding of each choice offered, it would have been necessary to define each one at length, which might have introduced the author's views too directly into each question.

The form of Qu.19 assumes general agreement that there is a shortage of skills across the board. No respondent disagreed, but there was variation, evident from the Tabulated Data, in the seriousness with which shortages were viewed. One respondent found only a single category of skills 'seriously and critically' lacking, and found the shortage 'not very significant' for five other categories. Four other respondents found seven or eight categories 'seriously and critically' short. Such variation might reflect personal styles of response, whether phlegmatic or excitable. Yet it also suggests a greater

divergence of viewpoints on the state-of-the-art in Pakistan, than might be apparent from responses to Qu.15.

The other factors in this section [Qu.s 20-22; p.18] were not enquired into on a nationwide basis, as the state of other people's 'nuts and bolts' is much less widely known than the general situation of staff skills. It was also felt that respondents would be more reluctant to state objectively the shortages of skills in their own work, as compared with the problems of plant or equipment. The individual plant, transport and equipment situation can change rapidly, as in the case of some centres that moved into new purpose-designed buildings. The comparatively new Federal centres were also in a stronger position for initial capital finance, although they were all running in rented premises, awaiting new constructions.

Since numbers served had generally increased [Qu.1], it is not surprising that there were many complaints of a lack of space for activities and play, and some lack of flexibility [Qu.20]. The remark that "*more could be achieved even in existing space with more imagination and energy*" no doubt is widely applicable, yet it is also true that Pakistanis tend to be culturally adept at managing activities in spaces that would be considered grossly over-crowded in many Western communities. When these respondents do complain of over-crowding, it is likely that there is indeed a serious problem, exacerbated by a lack of accessibility and problems of heating, cooling and noise.

Many centres have started in whatever rooms they could find and afford, regardless of suitability. Yet in the long run, inadequate or hazardous premises lead to staff burn-out and the progressive deterioration of quality. The fact that most buildings in Pakistan, of whatever sort, suffer from some design problems, noise and the extremes of climate, does not lessen the hazard to mental handicap services. Staff may be able to 'cope with' these familiar problems, but are unlikely to raise their sights and maintain the necessary enthusiasm when hampered by an inappropriate and ill-equipped environment.

Many respondents (12/16) felt their work was to some extent hampered by lack of equipment [Qu.21], but this was not seen as a major problem. The level of staff skills also enters into the equation. One respondent foresaw that as her staff became more capable and sophisticated, they would be seriously under-equipped for the sort of work they could be doing. Other respondents, involved with more straightforward educational work, saw the problem in terms of staff needing to use more information and imagination to create equipment out of locally available material. Here, questions of curriculum are also pertinent.

For example, the social and cultural norms in the North West Frontier are such that families expect mentally handicapped older girls to have a domestic future. The desired 'curriculum' for them consists of cooking, household management and an involvement with younger children. The equipment for this program is all readily available. The situation of older boys is more complicated, as many families hope that their sons will learn marketable skills, against a labour market evolving towards increasing mechanisation. To prepare these boys adequately a great deal of equipment could be used, but this is beyond the resources of local welfare organisations. The situation in Karachi or Islamabad is again appreciably different from that in Peshawar.

Most respondents had, or expected to have, problems with vehicle transport [Qu.22], which is one of the additional 'costs' of running area day-centres as opposed to residential work, locally integrated education or home-based schemes. (In fact, local schools and home-based schemes may not entirely

escape transport problems). With the exception of Islamabad, Pakistan's cities all have monumental traffic congestion. There are mental handicap centres where 12-, 15- or 25-seater wagons (loaded respectively to carry from 25 to 50 children) use up to 3 hours in pick-up daily in two or three circuits, and a little less time dropping children home after school. In cities with more than one special school, there is not yet much coordination of catchment areas.

Possibly the rising cost of fuel and vehicle depreciation may eventually force more centres to streamline their transport commitment, reduce their catchment area, or give preference to children who can make their own travel arrangement. All these strategies have been used from time to time in Peshawar, though it is unpleasant to have to reject a distant and poor family in favour of a nearby, wealthy one. Where families arranged to pick up their child in the afternoon, it was a regular occurrence for such arrangements to break down, so that a member of staff had to stay behind for an indefinite period until the child was picked up. The occasional attempt at kidnapping pupils, by feuding relatives, also made such arrangements less satisfactory.

6.2 (c) Financial Support & Public Awareness

Some connection might be expected between the level of financial support to services and the level of public understanding of mental handicap, but the survey provided no evidence for such a connection. Respondents believed that awareness [Qu.s 6, 7; p.12] had risen slightly over five years, while fund-raising [Qu.s 4, 5; pp.11-12] had remained the same (5/15) or become harder 7½/15). Given that most of the centres had increased their clientele, and thus probably increased their expenditure, the fund-raising picture was depressing.

One of the purposes of Qu.5 was to obtain general information about funding sources, a subject on which heads of institutions tend to be reticent. By listing most of the possible sources, a good level of response was received. Two more that should have been listed are 'District Council or City Council' and 'Investment Profit'. The author knows the latter to be a substantial income source for at least one centre, though no respondent listed it under 3.9 (Other). Not all the respondents are in fact responsible for financial management of their work, nor would they all necessarily be able to estimate accurately the cumulative effect of inflation on fundraising over the previous five years. However, their estimates of changes in income to their work are probably nearer the truth than an outsider's guess would be.

Two Federally funded respondents marked Qu.5 'not applicable', as they did not need to 'raise funds'. If the other 14 respondents had received funds from each of the nine listed possibilities, there would have been 126 ticks under either a, b or c. In fact, the total of ticks was only 60/126. This suggests that, for many of the centres or organisations, there may be some possible sources of income which they have not yet tapped. Of 60 sources ticked, 28 were giving 'same', 23 'less' and 9 'more'. This does not necessarily mean that the level of support has worsened dramatically - it depends how big the reductions have been, whether the reducing sources were major or minor parts of the whole budgets, and how far expenditure has increased. The present survey did not attempt to probe into these more complex and intimate details.

Fees and 'Regular Local Fundraising' were the most common sources (10, 10), followed by Federal Government (8), Provincial Government (7), Membership Subscriptions (7), Overseas Agencies (6), Zakat (6), Special Events (3). The two most common sources had been fairly stable [responses both being: 2 more, 7 same. 1 less]. The main changes perceived by respondents were that less support was coming from Federal and Provincial Governments [11 less, 4 same, 0

more], while Overseas support was variable [3 more, 3 less, 1 same (this one appeared under '5.9 Other')]. The perception of a drop in Federal and Provincial Government support may not necessarily reflect a smaller available 'pie', so much as an increase of applicants for a slice of the same pie.

Despite some difficulties over financial support, respondents were mildly positive about the level of public awareness, seeing some improvement both among the 'educated' (14/16) and 'the masses' (12/16). Differentiation between mental handicap and illness was also thought to have made progress, over five years, among the educated (12/16), but less so among the masses (7/16). These impressions are, as one person wrote "mostly guesswork", but the written comments indicate that respondents could give some grounds for their impressions, e.g. media publicity, lessening of stigma. A link with financial support for services might become better established if the public understood more, not only about what mental handicap is, but also about what positive steps can be taken, in prevention, education and management of the condition.

Issues of public awareness are also connected with fads and fashions in terminology [Qu.3; p.11]. As the public becomes more aware of the complexity of the field, it should be able to absorb an extended vocabulary. However, 'too much, too soon' might be merely confusing. Professionals may do better to use more readily understood terms in public awareness-raising. Many respondents gave two choices of terminology for their 'newspaper article', so the total of named terms is 29. 'Mental Retardation' (7/29) and 'Mental Handicap' (6/29) were most frequently chosen. Although the most-often chosen terms are those first listed, there is evidence elsewhere in the survey that respondents were not easily swayed by such factors as list order. Some might, of course, have been influenced by the survey title: *Mental Handicap* Services.

Many of the respondents are involved with special education, which may be why 9/29 chosen terms are connected with this activity. The comparatively few choices of 'Intellectual Impairment, ...Disability, ...Handicap (together 3/29), reflects the conclusions of a debate on terminology at a national meeting in Islamabad around 1985: the word 'intellectual', if it conveys anything at all, is associated with high intelligence and academic prowess, and is merely confusing if used in connection with mental handicap.

There is perhaps some danger of over-emphasizing the issue of terminology, which tends to rouse strong, if ill-informed, sentiments. One well-known educationist complained to The Pakistan Times that "Most of the children admitted to this [School for Mentally Retarded Children] are psychic cases and to brand as mentally retarded is highly objectionable" (Bokhari, 1989). Another educational author recently wrote several pages on "mental deficiency" in terms of "idiocy, imbecility and feeblemindedness", perhaps quoting (unacknowledged) from a Western text of the 1930s (Quddus, 1990, p.138-142). Both examples indicate a lack of familiarity on the part of these educated writers, which reflects the general lack of public awareness. Issues of definition and categorisation are discussed in more detail in Appendix II.

6.2 (d) Self-Advocacy & Parent Involvement

Formal self-advocacy [Qu.8; p.13] has evidently made little impact: only 2/16 stated that they were involved with any self-advocacy activity. In neither of those cases, so far as the author is aware, does any organised, regular meeting take place where mentally handicapped people consult together to formulate their views. The two claims to be involved with self-advocacy may be understood rather in the sense of a sympathetic encouragement and listening to older pupils in special schools. This in itself is by no means a negligible

involvement, and in fact may be a necessary step on the way to self-advocacy groups of the sort that have appeared in some Western countries during the 1980s and have secured their rights to speak at national and international gatherings on mental handicap. At least one Karachi organisation has reported (elsewhere) that it has facilitated the formation of a self-advocacy group.

Respondents had mixed feelings about the probable impact of self-advocacy in the future [Qu.9; p.13]. It will be interesting to see how far this movement develops, or is found appropriate, in Pakistan and other Asian countries. There are mentally handicapped people, known to most professionals, who have little difficulty making their individual wishes known, and indeed of dominating their families. There are some who clearly enjoy, and make a living from, traditional roles such as livening up weddings and social occasions by dance and tomfoolery. Whether these, or other, individuals would wish to associate with one another in advocating joint interests, as 'mentally handicapped people', is not at all obvious. And if some were interested, it is far from clear how they would obtain any representative views across the complex diversity of ethnic, linguistic and social class situations in which Pakistan's mentally handicapped people find themselves - a diversity that has yet to be investigated by trained socio-anthropologists.

Pakistanis tend to identify themselves strongly in terms of their family and extended family group, their language and their religious sect. Even in the cities, people still generally know 'who they are' and where their roots are. To assume an identity as 'a disabled self-advocate' and to make common cause with strangers on the basis of having a disability (and one that is not widely understood but in practice is generally stigmatised), is not a likely or obvious activity. It might be interesting or useful to try it, but people reared in the cultures of Pakistan may be less disposed towards this sort of action than the comparatively rootless and alienated modern, urban Westerner.

In many Western cultures, there is a presumption that from early adulthood people (of normal ability) will become largely independent of their parents and will independently make major life decisions about career, marriage, housing, children etc. The Western 'normalisation' movement has therefore encouraged mentally handicapped people in the same direction of independence. In many Eastern cultures, however, the Western habit of letting normal young men and women make major decisions independently, on the basis of their inexperience and immature judgement, is viewed at best as an incomprehensible Western aberration, and at worst as destructive abandonment. From such a viewpoint, it is naturally considered mere folly to encourage mentally handicapped young people to develop views of their own and to attempt to advocate their own cause. (Discussion on issues of independence and legal responsibility is quoted from early Muslim sources, in the second part of Appendix II, pp.49-50. See also p.34).

In the light of local cultural attitudes, it is understandable that parent- or family- controlled activities [Qu.s 10, 11; p.13] have made more headway, with 10/16 respondents already involved and 10/16 expecting increasing input from this quarter. Three among those already involved remain 'unsure' whether this movement will grow, while two of those not now involved do expect that it to grow. The Karachi organisation 'Parents Voice' attracted some compliments. One respondent, however, noted that parents' wishes and demands may change over time, making it hard for professionals to collaborate in a balanced way.

Understandably, families may start with the needs and situation of their own handicapped member foremost in their minds. Not all of them succeed in moving

on to form a broader picture of the needs of many mentally handicapped people, among whom their own relative might be typical or very untypical. Some centres and voluntary organisations have gained particular strengths through meeting the needs of a few children of committee members, while others have found their progress blocked or diverted by particular parents who make their own interests paramount or who are unwilling for resources to be used for purposes that will not directly benefit their own relative. (A similar failing may, of course, be found among professionals who are inclined to devote organisational resources to furthering their personal career and interests, regardless of whether these are also in the general interest).

On the other side, some respondents clearly wished to have more parent involvement, but were defeated by lack of time, place and money to arrange regular meetings and a meaningful program of home-centre collaboration. The 'Parents Voice' magazine (in both English and Urdu) is one way to bridge the gap, giving families some feeling of involvement and a forum in which they may express views and discuss issues. To families, such a forum can be of great value, whether in the form of personal meetings or a magazine.

The value of meetings became apparent in the earlier days of the Frontier Association for the Mentally Handicapped, which was run jointly by relatives and professionals. At one meeting a discussion was programmed, on the stages of personal adjustment of parents as they came to understand the condition of their mentally handicapped child and what it would mean for his or her life. As a basis for discussion, an 8-stage schema of 'personal crisis management' by Schuchardt (1980) was simplified by Mr Oliver Caleb, and presented to the parents (in Urdu). In previous meetings it had been difficult to get parents to express any views, so it was expected that discussion would last about 15 minutes. In the event, parents were busily debating an hour later, and carried on through the refreshments period. All the points that had been omitted, to simplify the crisis management schema for easier presentation, were raised and reinserted by one parent or another. It became clear that many of them had a great deal to say, and a great need to say it, once they found themselves in a sympathetic forum with other people who had had comparable experiences.

6.2 (e) Extent and Relevance of Services

In Qu.12 (p.14), the author made a statement that he considered generally accurate, though slightly provocative, and invited respondents to look for anything in it that they might disagree with - always a hazardous procedure among a circle of educated people. The fact that 9/16 did challenge some aspect gave a reassuring sign that respondents were not taking the path of least resistance. The nine disputants produced some 13 objections or comments (see p.14). Five stated that services (their own or others') did reach some children who were poor, lived in slums or were from rural areas. Four stated that some children with severe handicap were reached by services. There was also one general point about disability levels, two comments about integration of disabled children in rural areas or urban slums, and one technical point about comparative prevalence (which unfortunately could not be deciphered).

The terms of the original statement were not clearly defined, so there was ample room for disagreement. It is generally accepted that around 70% of Pakistan's population live in 'rural areas', though this figure may be modified when the 1991 Census data appears, and can also be modified according to how small a town is defined as 'rural'. It is reasonable to suppose that a similar proportion, i.e. about 70%, of mentally handicapped people also live in rural areas. Yet here, two reasonable qualifications were advanced: there

may be a differential mortality of severe and profound disability in rural areas, where nutrition is poor and medical services weak. That could reduce the number of people with severe mental handicap. Also, those with a mild level of mental handicap may be less noticeable in communities where there is less demand for intellectual prowess. In effect, the person who learns and thinks slowly may be under less handicap, and may not even notice any disability, where there is comparatively little to learn and where quick thinking is seldom needed. (The issues are discussed also in Appendix II).

Comparisons of the severity of handicap of clients in the different centres and service provisions are somewhat impressionistic. It is encouraging to know that several centres are taking up the challenge of people with severe and multiple disabilities, often with severe behavioural disturbance. At the same time, one respondent pointed out that most mental handicap is mild or moderate. (This is so according to normally accepted Western classification, but it remains arguable how far Pakistan should accept such a classification, based as it is on social criteria from significantly different societies). It seems that there remains a wide range of admission criteria between the various service centres. One or two will never turn a child away for being too difficult and complex, while several others will not admit children if their disability or behaviour is too problematic. The others fall somewhere in between. It would be interesting to investigate further these admission criteria, and how they are changing over time.

Qu.s 12 & 13 intended to elicit reactions to the fact, which none disputes, that existing formal services reach a small proportion of all the mentally handicapped people who could benefit from help. Responses to Qu.13 (p.14) were more positive than expected, with 9/16 claiming some effect on slum dwellers. Of these nine, five also extended some services to rural areas by means of outreach programs or through centre-based counselling used by rural visitors. (Three respondents were in fact reporting on work in rural towns, one of which is quite small and all of which are quickly accessible to open countryside). Even where respondents thought their work had no effect on the rural or slum population, comments indicated that these needy groups were not forgotten, and that further efforts were planned in their direction. (New strategies that use existing resources to have a bigger impact are discussed in Appendix IV).

6.2 (f) Information Resources & Mutual Help

Possession or access to written material relevant to the respondents' work is not entirely lacking, but is patchy and needs review and improvement. Qu.14 (p.15) was cast broadly. Ideally each section would have had 16 positive responses, for both possession of a personal copy and access at work. The potential total was 224 (7 x 2 x 16). There were 77/224 positive responses, which gives some indication of the information gap. Qu.14 should have had space for comments. It could also have asked specifically what respondents would like by way of additional professional information, reading or visual material. Most of the relevant publications of UNESCO [14.4] and the ILSMH [14.3] would be free on request, to organisations and service centres. The Mental Health Centre has tried to supply material under sections 14.2 and 14.5, while 'Parents Voice' has been available under 14.6, all at low cost or free. It appears that more could be done by these organisations to circulate their material, and more by the respondents to acquire what is available and to make it accessible to their own staff and juniors. (See also Appendix IV).

Over the past 6/7 years, the circulation of mental handicap centre/ organisation/contact address lists by the Mental Health Centre and the

Directorate General of Special Education seems to have facilitated mutual visits and the exchange of news and information between centres. Several respondents have in fact produced occasional pamphlets or magazines, in Urdu and/or English, and it has become normal for them to circulate at least 30 or 40 other centres with whatever they produce. Staff of many centres have also met from time to time on NISE courses and other training exercises, e.g. those organised by Dr Khalida Tareen, Dr Nusrat Awan, and Ms Meher Hasan.

These levels of mutual cooperation are reflected in responses to Qu.s 16 & 17 (p.16), which suggest either stability (22/44) or a modest improvement (14/44) over the past three years, with only 2/44 reporting a worsening. Although the question was asked generally, most responses probably related to the experience of the respondents' own work or centre. The greatest improvement clearly came between NGO and NGO (9/16). Those reporting less or no cooperation broadly tally with the responses on financial support [Qu.5]. While mutual cooperation is generally viewed as a good thing, respondents were not all sure whether they would have time for more of it [Qu.17]. Given the nature of Pakistani society, where much time is used in affirming links and inter-connections, it is interesting that only 8/15 were positive that they would have time for more mutual activity, while 6/15 were unsure. Some respondents were clearly aware of the limits placed by their own shortage of staff and resources. In fact, shortage of time and weaknesses of travel and communications facilities nationwide have been major factors in aborting several attempts to form a National Federation of mental handicap organisations, for which the need is clearly evident.

6.2 (g) Incoming Trends & the East-West Balance

Qu.18 (pp.16-17), listing 'topics of current Western interest and attention', may be predisposed towards responses in the (a) 'very important' category, given the extent to which Western experience and culture influence Pakistan. Three respondents in fact gave straight 'a's, but one qualified this by commenting that he did not think the importance of these topics would actually be recognised by his colleagues. Overall, there were 140 responses, of which 84/140 were 'very important', 41/140 'of modest importance' and 15 'not very important' ('now and in the next 2 years in Pakistan'). There were a number of additional comments, among which were several specific remarks about educational integration, realistically noting the practical difficulties.

The qualifying comment mentioned above indicates some of the possibilities for different interpretation by respondents (cf discussion on p.24). However it is interesting to see how the different topics compare with one another, and to note those which failed to arouse universal enthusiasm. The favourites, both scoring 13/16 'a's, were the two prevention topics, 18.6 and 18.9. The first, genetic counselling, is of course emcompassed by the second. It might have been useful to list a number of other preventive measures, such as improved ante- and peri-natal care, more health and nutrition education etc, in order to discover which out of these was given highest priority. However, the author's impression is that 'genetic counselling' might still have come top, as it is one of the most specific measures and the need for it is highly visible to service professionals.

Many other preventive measures are seen as part of the long-term development of Pakistan, which will happen 'some day'. Meanwhile, every professional knows some families with three or more disabled children having the same inherited syndrome, where the parents intend to continue having more children. Each such case tends to be more memorable, and to arouse stronger feeling, than 20 or perhaps 100 cases where the causes can vaguely be ascribed to 'birth anoxia'

or 'untreated childhood fever'. Studies in Karachi (Hasan, 1971) seemed to suggest that genetic causes were a real problem but did not make a large contribution overall. Further, genetic counselling is very narrowly available and it tends to run counter to the widespread custom of first-cousin marriage, a custom that may be strongly motivated in terms of property inheritance.

Vocational training (18.3) scored 12/16 'a's, followed by legal rights (18.7) with 10/16. Both, again, are notable deficits in current provisions. Vocational rehabilitation is a topic that surfaces at every gathering and conference, without very much subsequent action. Against a national background of high unemployment and under-employment of urban young people, it is not an easy field to tackle. The 'legal rights' score was unexpected, in that there has been comparatively little use of law to obtain 'constitutional rights'. For example, all children are 'entitled' to education, but since there are school places for only 60% of them, and half of those drop out during the primary cycle, there remain millions of children with no prospect of education, regardless of their 'rights'. This is discussed regularly in the news media and is 'common knowledge', so it is unclear why respondents thought that legal action for the rights of mentally handicapped people might be an important current or incoming trend. No doubt it should be, but the chances of it happening seem rather slight (despite the long history of Islamic civil rights for mentally handicapped people, Appendix II, pp.49-50).

Two topics achieved noticeable negative scores: services for elderly mentally handicapped people (3/16 'not very important') and residence 'in the community' (4/16), although both also gained 7/16 'a's. In terms of Pakistani cultures, the negative scores could be expected. Life expectancy in Pakistan is still some 20 years shorter than in the post-industrial West. Elderly people are customarily looked after by their children or within their extended family, as are people with disabilities. In-family care does not always work very happily, and it is particularly strained in crowded urban quarters or in villages where the younger people have gone to the cities, yet it is deeply engrained in the cultures. This is unlikely to change quickly. There might be a 'problem of elderly mentally handicapped people' in Pakistan, but it has hardly drawn much attention, amidst the many other pressing social concerns.

Similarly, as discussed on p.30, 'independent living' is hardly customary for people of normal abilities, and is all the less likely to gain ground with those who are mentally handicapped. Families often suffer great tensions and difficulties with their mentally handicapped adult members, to the point where they may wish (and some act upon the wish) to place these people in some sort of residential institution where it is hoped that they will be maintained in a benevolently custodial regime. However, the idea of pushing one's mentally handicapped close relative out of the family home, to manage his or her own life with 'a minimum of necessary support', would seem to most Pakistanis a gross dereliction of both family responsibility and religious duty, as well as risking some incident or accident that would expose the family to public shame. This viewpoint may change in the big cities over the coming decade, but there is little sign of it changing yet.

Why then did 7/15 respondents score independent living as very important? It could be simply an example of the strength of Western influence, however inappropriate to the cultures of Pakistan. Such an interpretation is 'against the data', but it is borne out by a previous experience where there was an opportunity to cross-question respondents. The author once attended a workshop in Lahore, with experienced and senior Pakistani social workers. An American lecturer was describing the benefits, for former psychiatric patients, of

living independently: "We expect our children to grow up and move out of home and live independently, don't we? If our children seemed inclined to stick around, we would feel there was something wrong and would give them a bit of a push to help them stand on their own feet, wouldn't we?" The social workers all nodded or vocalised their agreement. The author asked whether they did in fact expect Pakistani youths to behave just like independent young Americans. They then agreed that, of course, in Pakistan there was no such expectation.

Many people, however, tend to expect that what Westerners are interested in today, must be the way forward for Pakistan tomorrow. This expectation is not entirely foolish, in that there has been much useful technological innovation that reaches the wealthier parts of Pakistan within months of it becoming popular in Western countries. However, there are other technological imports of much more dubious benefit, and socio-cultural imports that are inimical to the fabric of Pakistani society. Neither the custom of young adults leaving home and making their own life-choices, nor the custom of them living with their parents and being guided in such matters, is a bad custom in itself. Each belongs to a form of society that has evolved over many generations, with its own checks and balances, its own strengths and weaknesses. But to take social welfare practices that have developed on the basis of the one society and to transplant them indiscriminately to the other, makes little sense.

The extent to which imported Western mental handicap methods and ideas have undergone cultural and conceptual adaptation in Pakistan, was the subject of Qu.23 (p.19), and produced a considerable range of views. It had not been anticipated that respondents would choose several of the options together. In fact, 9/15 did so, using 5 different combinations and totalling 26 choices. Analysis would have been easier if a 'one choice only' instruction had been given, but the present mixture is more interesting, suggesting more of the diversity of thoughts and feelings people have on this issue. Option 23.4 (more input needed from other, non-Western, countries) is superfluous to the main question of balance between Western and Pakistani ideas/methods, a fact that respondents seem to have noticed. Although 23.4 was the option most often chosen (8/15), it is the only one that has always been chosen in combination.

The view that there was too much unadapted Western influence (7/15) was given slightly more support than the 'suitable blend' theory (6/15), which in turn just out-scores the belief that more is needed from the West. However, the differences in score are slight. Given the various combinations that were chosen, the scores might have been in reverse order of priority if only one choice had been allowed. It had been thought that 23.1, 23.2 and 23.3 would be seen as mutually exclusive, but in fact two respondents combined 23.2, 23.3 (and 23.4), and one combined 23.1 and 23.3. This did not altogether contradict logic (Western or Eastern). Even if one thought that activities were dominated by Western ideas/methods, it would still be possible to think so highly of these ideas/methods that one could state a need for more of them.

The implications of these choices are to some extent backed up in the comments given. It seems that respondents see an interplay of Western and Pakistani ideas/methods over a period of development. Initially a sizeable input was (and in some cases still is) needed from the West, to prime the pump and provide a framework. Given that foundation, indigenous ideas and methods can and must appear and be tried out, which eventually will supplant or grown beyond the original. This process is under way. Meanwhile, other, non-Western, input would be welcome. The respondents appear to picture themselves (or their staff, or the whole field in Pakistan) at different points along this development process, which may account for the diversity of views.

In fact, there has been some non-Pakistani and non-Western input during the 1980s. At least three people (two from Federal Government, one from Darul Khushnud, Karachi) have taken courses of training in Japan and returned to practice in Pakistan. The Government of Japan financed a UNESCO sub-regional workshop on teaching materials, and sent some Japanese consultants (Report of the National Workshop, 1987). A talented Korean teacher was responsible for one of the Lahore special schools for three years. From the southern hemisphere, several teams of Australians have conducted mental handicap and cerebral palsy workshops in Karachi and Islamabad. The Mental Health Centre had the benefit of a New Zealand social worker for 2 years. A Japanese neurologist has supervised the inauguration of an epilepsy clinic associated with the M.H.C. special school. The Japan League for the Mentally Retarded has also made finance available for translating some M.H.C. publications. There have, undoubtedly, been many other instances of Asian or Southern input.

Pakistan has not been an importer only. In recent years, a growing number of Pakistanis have participated in Asian mental handicap conferences, e.g. in Thailand, Indonesia, Hong Kong. There have been some exchanges with colleagues in India. Mental handicap informational and instructional material produced in Pakistan has made its way to many Asian countries, and further afield. Nevertheless, it must be admitted that there has been a considerable Western input of specialist advisors and publications. Recently, there has been an increase in the number of volunteer professionals (Peace Corps, British VSOs and others from Holland, France, Norway), working for two or three years in special schools and resource centres. It is too early to evaluate the effectiveness of this movement, or to determine how well these people have adapted their skills to a different culture and environment.

6.3 PACE & QUALITY OF DEVELOPMENT

The pace of development has varied through the 1980s. The decade began with a burst of activity arising from the International Year of the Child (1979), which continued into the International Year of Disabled People (1981). At the end of 1982, respondents to the earlier survey hoped to expand and improve their facilities, obtain more training for staff and make cooperative links nationally. They hoped that the Government might soon provide more resources and training courses. The plans were mostly realised, but over a much longer time period. Substantial Government aid was budgetted for 1983-1987, but the Government lacked experience and was slow to draw up appropriate plans to use this budget. The voluntary welfare agencies continued to be burdened by the mechanics of finding and maintaining premises, equipment, transport, staff and finances. The main focus of service continued to be special schools in the main cities. Conferences were organised periodically, and there were scattered efforts to produce attitude-change materials for the mass media. UNICEF engaged in some pilot projects for community-oriented rehabilitation.

During 1985 and 1986, the pace of events picked up again as the Federal Directorate General of Special Education and the National Institute of Special Education began to take initiatives, drawing on the experience of the NGOs and using the available budget. Meanwhile, many of the voluntary agencies had made contacts with overseas organisations for funds, advice and skills inputs, and had been broadening their range of experience. Mass media information efforts also continued, though with little evaluation. This period of faster growth and innovation lasted practically to the end of the 1980s.

During the five years (1986-91) mainly reviewed in the present survey, there has visibly been progress in the number and size of service institutions, in the start of nationally organised training courses, the entry of the Federal Government as a major player in the field, and the increased piloting of 'outreach' services. The actual number of people with daily or occasional involvement in mental handicap services, whether as providers, clients or clients' family, has grown considerably, together with the broader circle of their relatives and friends who would acquire a little second-hand knowledge of the field. The quantity of information at large in the field has also grown, as formal training has been added to practical experience, more printed material has circulated, and more centres have acquired expertise from abroad.

The pace of development seems to have slowed a little as the 1990s began, and the present period appears to be one of consolidation, with some review and reappraisal. This was partly to be expected, after a period of change. Another contributory factor may have been the changes of political power: there is usually some slowing of development while people wait to see what the incoming party's policies will be. Further, the Federal centres are passing from their initial growth phase towards a more routine situation. Divergences apparent in responses to the present survey indicate that some centres and organisations have benefitted much more than others from the developments of recent years. All are highly conscious of skill shortages. Many still function with limitated accommodation and equipment, and with chronic financial strain. Most are well aware of the sea of needs around them, from which they are able to meet only bucketsful. However, this awareness has resulted in some strategy innovations, in order to apply scarce resources with greater results.

The 1982 survey conclusions (pp.41-43) anticipated progress in prevention, early detection and appropriate infant stimulation, vocational rehabilitation, provisions for slow learners in ordinary schools, and greater availability of information to families and the public. An overview in 1987 (p.45) implied that issues of self-advocacy, leisure time, sports, legal rights, design of the environment, profound handicap, and education for personal relationships (a euphemism for sex education) were beginning to compete for attention. Looking back from 1991, these forecasts seem optimistic. There has been little progress in most of these areas. Around 1980, the author was approached about the feasibility of Special Olympics in Pakistan. Not until 1990 did this sports and fitness movement for mentally handicapped people actually begin, in Karachi. The first sports rally for disabled people is said to have been in Islamabad c.1989 (Special Education & Welfare Division, 1990, p.10), though other sports events for blind and deaf people have taken place earlier.

The developments that have happened, and the level of exposure to Western trends and experience, make heavy demands on the leaders of the mental handicap service field. The more they do and the more they know, the greater are the demands upon them for more than they can possibly provide. In the early phase of development, people gain some satisfaction by responding to a perceived need and setting up a service, where previously there was none. The obstacles to be overcome in starting a new service are many, and the successful innovator overcomes them steadily to achieve his or her goal. However, the achievement brings certain consequences that may be unforeseen.

Once a new service is started, its existence often reveals much greater need than was foreseen. Further, the initiators gain experience of providing the service and so raise their expectations of what ought to be provided, while at the same time demand for the service increases and threatens to overwhelm their small available resources. After a while, the 'halo' effect of doing

something new fades. Voluntary help may transfer itself to some other, fresh, innovative service. Aid agencies may have given pump-priming grants, which diminish over a 3- or 5- year period. These structural problems are compounded by a steady attrition of energy and motivation, caused by working in unsuitable environments. The innovator or leader is, of course, also as liable as anyone to ill-health, family crisis or accident. Similar problems may afflict Government efforts, but on a much larger and more impersonal scale.

These factors, which are not peculiar to the mental handicap field, make it hard to find any absolute standard for evaluating the pace and quality of development. Compared with 1970s provisions, the 1980s saw substantial service developments. Compared with the need and demand for services, the developments are feeble. Developments in one provincial capital, Peshawar, have been massive compared with those in another, Quetta. Yet compared with what could have been done in Peshawar, what was actually achieved looks rather modest.

Historical Comparisons

Developments in Pakistan are sometimes compared with the state-of-the-art in Britain, because of the historic links and considerable traffic between the two countries. Not surprisingly, mental handicap developments in Pakistan seem rudimentary by this standard, and there are diverse views about the usefulness of Western influence and knowledge. Yet in fact, though they started much later, some services have developed in Pakistan faster and in substantially different circumstances than they did in earlier days in Britain.

The following medico-pedagogical recommendations were published by Thomas Willis in England 300 years ago:

> Stupidity, whether innate or acquired ... though it be not usually cured, yet it is wont [*able*] to be amended. Wherefore the cares of both a Physician and Tutor must be used for polishing somewhat the understanding of such as are so affected, and that being brought to the use of, at least, some little Reason, they may be exempted from the ranks of Brutes. Therefore they are to be instructed in all things by an assiduous and very diligent Master, and the same things are to be inculcated again and again: For by this means the Spirits, though dull and torpid, will in some measure be actuated by perpetual Exercise; and being continually stirred up, will make at length for their Expansion some Tracts or Passages, though imperfect, in the Brain, how gross soever. (1689, London Practice of Physick, 497-502).

The spread of mental handicap knowledge and special educational skills in Pakistan may be seen with this perspective: Willis's positive attitude and suggestions were available for 200 years before much was done in England to act upon them. In Pakistan, as modern information has become available, people have moved much more quickly (20-30 years) to develop services and acquire practical skills, within the admitted constraints of the national economy.

Other parts of long-established knowledge, however, have yet to make their full impact in Pakistan. For example, the use of iodine to prevent goitre was first published in Switzerland in the 1820s, and a hundred years later (1923) came the first scheme for iodisation of a community water supply, in the USA, with consequent prevention of goitre (Kohn, 1975). Despite nearly 70 years' further interval, and the on-going efforts of UNICEF and the Government in salt iodisation (cf. Mull, Anderson & Mull, 1990), goitres are still common in the mountains of Pakistan and a number of other countries, and children are still mentally handicapped through preventable iodine embryopathy.

7.0 IN CONCLUSION

A 'sense of the trends in development', at which the survey aimed, has been discussed in the previous section (6.3). Admittedly, in a period characterised more by consolidation than by advance, the 'trends' are inconclusive! The author's main personal discovery from this survey is a renewed respect for the dedication and enthusiasm of his colleagues in Pakistan, who persevere with the aim of making room and encouragement for mentally handicapped people to grow and blossom, in generally adverse circumstances. The sole recommendation to the Government is that it should value these admirable workers and should make more effort to relieve their burdens and to build upon their strengths.

A more general conclusion is that there are very considerable resources of relevant knowledge and skills in the country, and of capacity to apply the knowledge and skills in development of concepts and in design of programs and equipment suitable for the future of Pakistan. Normally, these resources are uncoordinated. They are seldom harnessed or brought jointly to bear in the processes of policy formation, planning and implementation.

The present survey is a move towards coordinating some of the experience and knowledge. The intention has not been to produce a list of 30 things on which the Government ought now to spend money. That sort of exercise has been done at various conferences, with less than satisfactory results. Instead, this report has reflected upon the development processes, the better to understand what is actually taking place now and how the field is likely to develop; and how it could more usefully develop. Those who have taken part, and other leaders and interested people and those who are studying for a possible future role of leadership, may find their own views here set in a broad spectrum of viewpoints and collegial experience. From this spectrum, they must draw, and act upon, such conclusions as make sense in their own situation.

The recommendation to these active colleagues is that they should have confidence in themselves and in one another, whether they are teachers, parents, pediatricians, musicians, psychologists, therapists, lawyers, community mobilisers, genetic counsellors, writers, psychiatrists, pirs, administrators, film-makers, brothers or sisters, uncles, aunts or grandparents, religious teachers, sportsmen, social workers, artists, or whatever their capacity. The work of such diverse professionals and occupations will seldom be the same, but with mutual confidence and appreciation it can move forward over the same broad wave-front. This does happen, here and there, every day. But the people involved in moving forward are seldom aware of the broad progressive movement, and so lack the encouragement of knowing that others are moving with them.

Once again, this suggests the need to see the whole rehabilitation field as a complex information system, in which the resources of *concept, knowledge, skill and design* flow from person to person and may eventually result in the needed changes in society as a whole. This is not a patent conclusion from the present survey, but in reality it underlies the whole concept of pooling and analysing experience. As a set of broad development recommendations, the 'information' approach is outlined in Appendix IV.

The voices of families, advocating the interests of mentally handicapped people, are as yet neither prominent nor clear in Pakistan. The voices of mentally handicapped people, representing themselves, are not heard at all in public debate. Professionals in the many capacities listed above should anticipate, and where appropriate should facilitate, a greater involvement from these people, who are, after all, 'what it's all about'.

DEVELOPMENT REPORTS & OUTLINES 1980-88

Five reports and sketches, giving perspectives on development trends:

1. Development of Mental Handicap Services in Ruritania over Fifty Years. First circulated, *Feb. 1980.* (*Ruritania is a fictional country*).
2. Conclusions from Mental Handicap in Pakistan: Development Issues. Report of a Nationwide Survey (*M. Miles & L.V. Auret, 1983*)
3. Mental Handicap: Prospects for Pakistan, prepared for the Vth International Psychiatric Conference, Peshawar, *Dec. 1984.*
4. 'Notes on Program Areas' for Pakistan (*to 1987*), in International Directory of Mental Retardation Resources (Ed. R.F. Dybwad). 1990, ILSMH, Brussels.
5. Third World Disability: Myth & Reality. Peshawar, *Oct.1988.*

(1) DEVELOPMENT OF MENTAL HANDICAP SERVICES IN RURITANIA OVER FIFTY YEARS

GOVERNMENT & LOCAL AUTHORITY	*PRIVATE ORGANISATIONS & PUBLIC OPINION*	*FAMILIES & HANDICAPPED PERSONS*
Phase One No Government provision, & little official interest. "Too many other important things to be done". Normal schools catering for only 60% urban, 35% rural children.	A few private schools and homes run by philanthropists in big cities. Public ignorant of basic facts on h. people, seeing them as cursed by God or having evil spirit. No differentiation between mental illness and mental handicap.	Families with h. member get no help, no aids to rehabilitation. Much money spent on quack cures & fancy treatments. Great strain on family. Some h. persons become beggars. High rate of mortality from lack of adequate care.
Phase Two Goverment sponsors survey by medical researchers. Modest financial aid from local authorities to private institutions.	Slow build-up of public interest. "Something should be done". Local handicap societies raise funds & donate vehicles to special schools. Mass media items portray pathetic image of the h. child. Papers on handicap are read at medical/psychological conferences.	A few exceptional parents start an institution for their own & other h. children. Some shrink from the build-up of public interest. Some see it as their big chance, & use all means to publicise the needs of h. people & their families.
Phase Three Local authorities open some residential institutions, lacking properly qualified staff. Emphasis on handicraft work. Problems seen mainly in terms of finance & buildings. Some efforts to get staff trained.	More private institutions. Societies publish advice pamphlets for families with h. member. Pressure on Govt. to make more contribution & train doctors, teachers, in mental handicap. Media mostly portraying h. people as 'charity cases'. National Association formed to coordinate local action & represent voluntary agencies to Government.	Information spreads on how families may get help and adapt family life to make best of situation. Some families face difficult question of whether to place h. member in an institution. Concern is expressed about financial or sexual abuse of older h. persons.
Phase Four Enquiries into cruelty to residents in Govt. institutions. Laws to help h. people obtain work & rights. Government sets up Commission on Mental Handicap.	Voices of h. persons begin to be heard in societies & in media, asking for the means to help themselves with dignity & human rights. Concepts of normalisation discussed. First sports association for h. persons. Professionals showing more interest in careers in mental handicap field.	Dissatisfaction with institutional approach. Demand for a better deal & financial help towards costs of family supporting h. member. More literature available on teaching h. babies at home. Families begin to realise dangers of over-protecting older h. people.
Phase Five Change of emphasis from institutions & handicraft work to early intervention & family support, with integration of all h. children in normal school.	Experiments with smaller, family-style residential institution, with h. people encouraged to do as much as possible for self. Associations in court battles to obtain constitutional rights for h. people.	Greater diversity of jobs opening up for h. people. Many h. children far exceed original assessment of their potential. Questions arising about marriage for h. people.

Bracketed numbers in the following texts refer to notes, at the end of each piece, with the hindsight of 1991.

(2). NATIONWIDE SURVEY (1982): CONCLUSIONS (publ. 1983)

Among the wide range of views expressed, some general trends could be seen. Clearly many projects were pursuing similar courses and had met similar problems. More than half of the stated local aims were to expand and improve existing facilities: better buildings, equipment and more trained staff. A small number hoped to do something new: e.g. to get a fuller picture of the needs in their area, to begin non-institutional services such as parent/public education, to draw upon existing community resources. It would seem that the majority of respondents see themselves and their institutions as being the principal local resource, rather than perceiving the possibility of a role as catalyst and enabler of community resources.

Perhaps for the same reason 'cooperation' was mentioned as a desirable goal on the Provincial/National level, but not on the local/city level. There is more than one mental handicap facility in each of the major cities of Karachi, Lahore, Islamabad/Rawalpindi and Peshawar, yet it appears that modest cooperative links have more easily been formed and maintained across distances of several hundred miles rather than within cities [1]. Lack of cooperation and coordination was one of the most-often mentioned obstacles in present work and attainment of goals.

Perhaps the ambivalent attitude towards cooperation may relate to another often-mentioned obstacle: lack of trained, experienced staff. In the past there has been some interchange of staff between institutions in the same city, not often amicably arranged [*i.e. staff have been poached or enticed, or have left one school after a dispute and have set up a rival concern*]. From the staff point of view it is preferable that the opportunity should exist for movement and broadening of experience; ultimately it will help in creating a viable profession of 'special educator'. From the management side however it is obviously damaging to lose staff unexpectedly to a rival institution. Each time this happens, it makes cooperation more difficult.

The suggestion was put forward that the Government should play a greater part in development of mental handicap facilities, both at the policy level and in training appropriate staff. However, it is unlikely that the Government will take much initiative over the next five years, since it is very much a newcomer to this field and does not have the necessary resources to set up a training scheme. Such a scheme, to be of any practical value, would neccesarily be attached to an existing institution [2]. If a viable national training scheme does come into being, it is much more likely to do so in response to a joint initiative from the voluntary associations: such an initiative would require cooperation, coordination and an increased level of mutual trust, both between welfare associations and between Government and non-government organisations.

The issue at stake is whether the majority of concerned individuals continue to focus on their own immediate objectives or are able also to take in and respond to the broader needs of the nation. On the nationwide scale there are already sufficient resources of skill and experience within Pakistan to make possible the training of many more staff and the setting up of many more services. There are special teachers, psychologists, psychiatrists, speech therapists [3], physiotherapists, occupational therapists in various places

who have had some years experience of working with mentally handicapped persons. There are capable and energetic parents with experience of running local associations and of preserving some balance between the interests of families and the inclinations of professional colleagues. If most of these individuals could commit themselves to increased cooperation, sharing of time and resources, and an open-ended attitude towards further developments, then there would be real hope for progress. Responses to the present questionnaire indicate awareness of the need for such a commitment.

The question remains: how best can this mutual trust, commitment and endeavour be fostered? Is it possible to work towards formation of provincial and national bodies that will be genuinely representative, and will facilitate local development by providing information and resource services? The dismal example is well known, of national associations in other fields, which quickly degenerate into exclusive self-serving cliques, or which use up resources and energy on prestige projects serving merely to boost the organisers' ego. Awareness of the possibility may help to prevent it, since there is no reason why this pattern should be inevitable.

Some of the major problems and obstacles identified could well respond to joint initiatives from a coordinating body having the support and confidence of the majority of mental handicap rehabilitation professionals and parents. Three problems that were identified, i.e. the need for improved initial assessment and individual [*child*] program construction skills, the need for more and better vocational training opportunities, and the need for parent education and improved public attitudes, are areas where the pooling of resources and experience would be most valuable, without there being much threat of competition or of prestige-stealing. All projects and institutions stand to benefit from real advances in overcoming these needs and lacunae.

It is noticeable that the three areas of need just mentioned are cross-sectoral or inter-professional: provision of the missing parts requires either persons with more than one professional training, or collaboration between professionals from separate disciplines. The mentally handicapped child [*with a sufficiently determined family*] is likely to pass through the hands of several doctors, a psychiatrist or two, then on to psychologists who may run several assessment procedures, and finally to a teacher, collecting [*or, more often, not collecting*] various pieces of paper along the way. The classroom teacher, who will spend more time with the child than any of the other professionals, is likely to be the least educated and is usually unable to read English with any fluency. Clearly, the better-trained professionals should make their procedures accessible and provide them in Urdu, so that there is a proper exchange of information, recording of observations and participation by the front-line teacher in programming for rehabilitation of the mentally handicapped child. The same applies to parent counselling, public attitude intervention and vocational training.

Here again, the hidden obstacle may be that of professional mystique and demarcation limits. If assessment procedures are put into Urdu and made available to classroom teachers [4], the psychologist may feel that her professional secrets and associated prestige have been given away. If parents, teachers and therapists combine to tell a psychiatrist that they think a change of medication would be advisable, they may precipitate a defensive professional reaction. The team approach to rehabilitation does not happen without years of hard work and commitment on the part of those involved. Staff relations in Pakistan usually involve a rather stiff pecking

order according to academic qualifications. For this to evolve into something more useful can only happen through a deliberate effort of professional open-mindedness and the exercise of humility.

The same conclusion seems to have been reached in private comments by a number of people surveying the rehabilitation development scene: that politics and personalities constitute at least 80% of the battle; the remaining 20% is made up of needs for various resources. This indicates that the possibilities for development are largely in the hands of the people doing the work. So far as financial resources are concerned, the Government has budgetted Rs.83 Crore (equivalent to 65 million US dollars) for the period 1983/1987. Further large sums of money will become available through the Zakat Foundation [5], and in view of the incapacity for handling money by young mentally handicapped persons it will be possible to secure some of this directly for rehabilitation projects. Technical skills are increasing as more people gain experience in the expanding number of projects and special schools. There are also overseas agencies willing to help with workshops, short courses and consultative services.

Much of this potential can be wasted if the professionals and parents persevere with parochial interests, squabble over the distribution of resources, and put the prestige of their institution before the interests of the disabled persons they claim to serve. But this is certainly not inevitable, and there are unmistakeable signs of a moving together, a desire to cooperate, and an appreciation that ultimately everyone will benefit by mutual help. That is the challenge for the next decade.

[1] Distant links have in fact been tenuous. The cost of travel and lack of efficient telecommunications has made distant links hard to maintain.

[2] The Government established the National Institute of Special Education in 1987 for staff training, despite serious deficiencies in resources. The training imparted, like training in most fields in Pakistan, has been predominantly theoretical.

[3] The speech therapists in 1982 were all British women, only one of whom did in fact work for a while in a mental handicap school in NWFP. Subsequently she started an innovative Centre for Speech & Hearing, at Mardan.

[4] The Mental Health Centre took steps towards this goal in the Urdu version of Special Education for Mentally Handicapped Pupils.

[5] Little of the Government budget actually materialised. Use of Zakat funds has varied regionally, being of great assistance in some places.

(3). M.H. PROSPECTS FOR PAKISTAN (1984)

The past 15 years have seen a worldwide revolution in the prospects of persons with mental handicap. From a position on the edges of society, neglected, maltreated, pushed into corners or colonies and assessed solely in terms of their deficits, some mentally handicapped people have fought back to achieve a place of dignity, making their economic contribution, living independently, speaking up for themselves and being accorded full adult status.

The fact that only a few have achieved these goals does not detract from the reality of the revolution. Psychological and attitudinal barriers have been breached, rendering untenable the old maxims, e.g. that 'the severely retarded

person needs to be looked after for life', or 'no Down's syndrome person will ever be able to read and write', or 'mentally retarded people cannot compete in open employment'. Even if these outdated beliefs are still promulgated, they are steadily losing strength before the visible evidence of mentally handicapped people performing actions of which they are supposedly incapable.

In Pakistan the prospects are no less interesting, though a little different from those in economically stronger parts of the world. At the end of 1979 there were less than 10 institutions providing services for the mentally handicapped. Five years later there are more than 30 facilities and organisations for the mentally handicapped, and mutual collaboration is taking place both at provincial and national level. The pool of expertise and involvement, both parental and professional, has grown even faster. Much of the effort so far has been applied to basic tasks such as finding premises for day centres, obtaining equipment, recruiting staff and giving them elementary training, and discovering the financial means to stay afloat. The main target during this period has been the moderately to severely mentally handicapped person aged between 5 and 20 years old.

The next phase should see developments in prevention, early detection and appropriate infant stimulation; vocational rehabilitation for the older mentally handicapped person; an increasing unity and purpose among associations of families and professionals; improved provision for slow learners in ordinary schools; a major increase in the availability of information to families on how to manage at home; and a general improvement in public attitudes and acceptance of mentally handicapped people.[1]

Coming onto the agenda now are some questions of philosophy and practice, which can be answered only after serious thought about the various life-styles, cultural norms and family ambitions within Pakistan. The question 'How will mentally handicapped people live in the various strata of society during the next 20 years?' reflects upon the question of what to teach in special schools, and indeed on the question whether schools should be 'special' or 'integrated'. The reappraisal and uprating of the social role of mentally handicapped persons in the West has implications for Asian and Middle Eastern societies, which have to be worked out locally.

In some ways, mentally handicapped persons may have better prospects socially in Pakistan than, for example, in Britain. The twin western deities of speed and efficiency have only few worshippers in Pakistan. Most people's identity and self-image is still bound up with their family and local community, rather than with their profession and salary. A person who cannot read is not instantly consigned to the margins of Pakistani society. One who does not possess a micro-computer is not an object of amazement and ridicule. These pleasant features of life in Pakistan give the mentally handicapped person room to move and time to draw breath.

Above all, the mentally handicapped person needs *people* rather than *money* in order to live a worthwhile life: people who are concerned but not over-protective, who reinforce positive actions without being paternalistic, people who set no limits to the potential achievements of the mentally handicapped person. Pakistan is rich in human resources, rich in people, and there is no limit to the potential for positive integration of mentally handicapped people at every level of national life.

[1] Looking back from 1991, this was all rather optimistic.

(4). NOTES ON PROGRAM AREAS (written 1987, publ. 1990)

Counselling and Education - In 1978 there were 6 special schools; in 1987 more than 40 educational and training facilities exist for the mentally handicapped, and the pool of skills, experience and public awareness has grown steadily. Mental handicap in Pakistan is in transit from the medical to the education/social welfare field. Pediatricians and psychiatrists used to be the first and last professional points of contact for families: they are now able to refer onwards to educational facilities, a shift of emphasis that is enlarging both the rehabilitation potential and inter-disciplinary tensions.

Personnel Training - Some personnel with backgrounds in pediatrics, psychology, child psychiatry or social work have taken training abroad in modern approaches to the mentally handicapped and are now informally training special school staff on-the-job. Formal Government-sponsored training started in 1986, and will use distance learning methods from 1988. [1].

Residential and Community Services - Some large, segregated institutions with residential facilities have recently been constructed on the basis of earlier plans and attitudes, while more recent trends of thought have resulted in *[some experimental]* integrated schooling of handicapped children in Sind Province and some community-directed rehabilitation developments in Punjab and the North West Frontier. One self-advocacy group exists, in Karachi.

Planning and Present Trends - A national survey of mental handicap NGOs indicates that plans and priorities have centred on extending existing institutions and counselling services; and discovering professional and financial resources to achieve this goal. Respondents identified lack of professional skills, negative public attitudes and lack of coordinated efforts among the major obstacles. Items such as self-advocacy, leisure time, sports, legislation, architectural design, profound mental handicap, education for personal relationships, were hardly on the agenda. Yet the exposure to international currents of thought is considerable, and these more sophisticated demands are beginning to compete for the limited available resources of time and personnel.

[1] In fact the distance learning (Open University) courses were delayed, and may begin in 1991.

(5). THIRD WORLD DISABILITY: MYTH & REALITY (1988)

The diagram overleaf shows, in abbreviated form, some of the main disability development myths propounded by assorted Western 'experts' and U.N. agencies during the 1980s. These myths arose from a combination of ignorance, emotional responses to people in difficult situations, patronising attitudes, simplistic ideologies, and an unwillingness to undertake the difficult task of studying the complex realities and diversities of Third World countries. The propagation of these myths has further delayed formulation of realistic policies. Some of the myths have begun to be exposed as obstacles, but they all retain some power to arrest development.

MYTH	RESULT OF MYTH	REALITY	RESPONSE TO REALITY
1. Number 10% of the population of the world are disabled.	Disbelief. Numbness.	About 3% are perceived as disabled.	Attention. 'Something should be done'.
2. Description 'Disability' is a label created by society to add to the total of oppressed and marginalised people.	Belief that these 'artificial' problems of disability can be overcome by overthrowing the oppressors & changing the terminology.	Whatever the sociological context, the ability to see, hear, move, speak, is highly prized. Most D.P.s perceive their disability as a major feature of their life.	Revision of terminology is a continuous, minor, part of attitude change. It should lead, but not lose touch with, public opinion.
3. Current situation Nothing is being done for disabled people in the rural Third World.	Erases indigenous efforts & traditional knowledge & skills. Attracts wild-eyed romantic idealists, rugged pioneers. Promotes notion of 'doing things for the disabled'.	Over 90% receive daily care & attention from family/ neighbors. An unknown number so adapt as to minimise the adverse results of their disability. Main resources are their own abilities and those of their families.	Assistance should start with the self-perceived needs and resources of D.P.s, their families & neighborhood; then build on already existing knowledge, skills & technology.
4. Proposed action (a) Prevention must have top priority. (b) Focus on rural women, early intervention, community based programs, human rights, integration, normalisation.	(a) Focus on finding the scientific 'fix' for the human 'problem'. (b) Harangued by Western slogans, Third World officials react with polite disbelief & token compliance.	Prevention lacks credibility if nothing is done for/with people already disabled. Scientific 'fix' is seldom useful unless understood by the people who must deliver it. The problem, as locally perceived, is of D.P.s crawling on ground or led by the hand, begging in bazar.	Start with perceived problems & locally available knowledge & resources. This can broaden out later, as experience & credibility build up. It will then include prevention, early intervention, etc.
5. UN/Government roles The UN must lead, and encourage Governments to act for the poorest, most distant, deprived, disabled and difficult to reach.	Fosters pious rhetoric, conferences & paperwork. Leads to token 'display' models in capital cities. Ultimately the UN Decade of D.P.s has achieved not much more than Govt.s would have done anyway.	The UN bleats slogans on the sidelines. In political terms Govt.s gain nothing by helping rural D.P.s. But, if mobilised, Govt.s and U.N. have extensive capacity for training and communication.	Govt.s should start with easier & nearer tasks. UN & NGOs should aim to maximise circulation of rehab information & skills, using Govt. resources to multiply & upgrade them.
6. Western wisdom Third World Governments should learn from the mistakes of the West and avoid repeating what the West did 30 years ago.	Foreign advisors fail to see that what they think of as mistaken or out-moded, may suit the level of socio-economic development in the target nation.	Services correspond with prevailing attitudes, which change slowly in response to new ideas, technology, and changing social trends.	Plans should start with current attitudes & aim to facilitate change, but not so quickly as to lose touch with public opinion.
7. Employment Rehabilitation should produce self-supporting, independent-living, fully participating citizens	Empty rhetoric produces incredulity & promotes tokenism. A few 'Super-Cripe' are paraded. A reserved job quota is ordered but not enforced.	Third world countries are less dominated by the 'work ethic' & individualism. 'Independent' living is seldom a desired goal. Mutual dependence & support is the norm.	Start with local view of mutual aid & employment. Assist home-based cottage industries for D.P.s to pursue as members of families or disabled persons' cooperatives.

APPENDIX II

PROBLEMS OF DEFINITION & CATEGORISATION

The first paper below appeared in the Report of the National Coordination Conference on Education of the Mentally Handicapped, July 1985, Islamabad, pp.80-85, Directorate General of Special Education, Government of Pakistan. It is followed by some notes on the historical Islamic understanding of terms for mental handicap, and by an 'alternative' rural point of view on the categorisation of children's abilities.

Many different words and phrases have been used to describe the world-wide phenomenon of mental retardation. No single definition can be suitable for all times, places and uses, because people's perception of mental retardation varies according to their background, level of education, environment, profession, state of economic development, and so on.

In Pakistan, for example, in the family of a non-literate agriculture labourer with 8 children, if one or two children complete primary school and can read and write a little, the parents feel pleased that some of the family 'got educated'. But compare them with an upper class Karachi family with four children, of whom one becomes a doctor, one an engineer, one a psychologist and the fourth completes 5th Grade before dropping out of school. This fourth child will be considered mentally retarded, because he has the disadvantage of being born into a high-achieving urban family instead of a rural labouring family!

In the North West Frontier Province (NWFP), if a census enumerator visits a house and asks a lot of questions about the members of the household, how many females, what ages etc, he runs the risk of being abused. If he asks 'In this family is there any *pagal* (mad person) or *nim pagal* (half-wit)?', he may land in serious trouble. The chance of gaining accurate information is small. It is normal to conceal the presence of a handicapped child.

Even in 1985, in some economically advanced countries, it may be several years before parents become aware that their child is mentally retarded. They may be conscious that she is developing slowly. But it may not be until the age of 5 or 6 when the child starts school, that they realise she has fallen far behind other children. Western professionals are cautious nowadays about putting labels on children. Children develop at different rates. Some are slow starters, but catch up later. Some never catch up, but they can still benefit from ordinary schooling. But once the label 'mentally retarded' has been fixed on a child, the parents and teachers tend to develop a negative attitude; they expect the child to achieve little, and the child acts down to their low expectations.

Among mental retardation professionals, the past 20 years have seen a consistent upward revision of expectations of what mentally retarded pupils can achieve. Children with Down's Syndrome used to be classified as 'severely retarded'. Experts used to give their firm opinion that Down's children would never be able to read and write. It is now understood that there is a variety of potential in these children. In 1985, hundreds of Down's children have learnt to read and write. We have three at the Mental Health Centre, who have begun reading and writing numbers. Within two or three years they will possess an ability that half the adults in Pakistan do not have. Already one of our Down's children can write her name, while the school sweeper cannot write his name. So which one is mentally retarded?

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Why are definitions needed? Government officials want to know how big a need is before they start making provisions for that need. Normally this is a sensible and logical attitude. But in the present case it not be feasible, because mental retardation is not a logical or static thing. It varies according to one's viewpoint. For example, some Western countries used to say 'Special schools must be provided for all children with IQ under 55. So all children must be tested, to know how many fall into this category.' Many of those countries have now abandoned this approach, for several reasons:

(1) IQ testing has fallen into disrepute, because IQs are inaccurate in predicting achievement, are liable to cultural and racial discrimination, are dependent upon the child's cooperation and emotional state on the day of the test, and various other reasons.
(2) The whole concept of special and segregated education has been called into question. In Italy for example all children attend normal classes, even the severely and multi-handicapped, unless it is physically impossible for them to be in the classroom. In other countries a more gradual approach has been adopted.
(3) When systems are set up that depend on a particular cut-of point, e.g. IQ of 55, they soon become rigid and inflexible. Then the child with a test IQ of '54' finds it impossible to move to a different educational category, even though she is showing abilities superior to those of some children with a test IQ of 60.

'Mental Retardation' varies with the level of personal involvement. Among better educated families in NWFP, it is common to say that the child has a "speech problem". Razia is 6 years old but she manages to say only ten words, so she has a speech problem. In fact, Razia is not toilet trained and does not feed or dress herself. When it is suggested to the parents that she is mentally retarded, they say "No, no, she has a speech problem".

In the West, epidemiologists and demographers no longer ask "How many mentally retarded children do we have?" The question is virtually impossible to answer even with Western resources. One can talk only of trends and probabilities, based on intensive study of sample populations.

The perception of mental retardation is partly based on age. If a child aged 10 years is behaving like a 6 year old, it is noticeable and incongruous. If the child aged 10 years is behaving like an 8 year old, it is less noticeable. And if we meet a child who is behaving like an 8 year old and we do not know that in fact he is aged 10 years, we are unlikely to jump to the conclusion that he is mildly retarded. So as far as mild retardation is concerned, the birth certificate causes the perception of retardation. In countries where the majority of births are not registered and where many parents are vague about their child's age, it is impossible to discover the norm of 10 year old behaviour, and to judge whether a given child is appreciably below this norm. In practice, some NWFP families seem to report their child's age on the basis of his behaviour, rather than the other way round: a child whose age is first stated to be "4" comes along 3 years later and the parents now state that his age is "5".

A different approach

What is the educational problem found with Muhammad Ali? He takes longer to learn things than others do. It takes many repetitions to fix even a simple fact in his head. His retention is short. His attention soon wanders. Those are the actual problems. It is not necessary to speculate about 'brain damage', or define his 'mental retardation'. For educational purposes he is a

'child with learning difficulties'. Looked at from the official point of view, he is a 'child with special needs'. These phrases have the advantage of recalling that Muhammad Ali is first of all a child, not just a problem.

The official mind then may reasonably enquire, "How many children have special needs? How 'special' are their needs?" In every Western nation the answer discovered over many years is that there are more special needs than there are therapists and special teachers currently available to meet those needs. For an adequate response to the special needs there are not enough physiotherapists in the USA, not enough speech therapists in UK, not enough teachers of the blind in Germany, and so on. There seems to be no danger of over-providing in Pakistan.

Let a start be made with personnel training and various sorts of special education provision. As schemes develop and experience is gained, the concerned officials will develop their understanding of the range of disabilities and of rehabilitative measures, They will come to realise in practice what information they really need and how they may obtain it, because their own viewpoint will change as experience builds up.

The following is extracted (pp.128-129) from M. Miles (1981) 'Some Historical Notes on Religions, Ideologies and the Handicapped'. Al-Mushir (The Counsellor) 23 (4) 125-134, published by Christian Study Centre, Murree Rd, Rawalpindi.

.... we find among the schools of legal interpretation in the 8th and 9th A.D. a detailed discussion of the rights of the mentally disabled person, nearly 400 years before the first English legislation and anticipating by a thousand years the current Western debate on the same subject, with efforts to define and discriminate between various types of mental disability and their behavioural consequences.

Thus in Islamic Law we find the following "A light-minded person (Arabic *safiyah*) signifies one who in consequence of a levity of understanding acts merely from the impulse of the moment, in opposition to the dictates of the Law and of common sense. Abu Yusuf, Muhammad and as-Shafi'i maintain that such a person is under prohibition, and is interdicted from acting with his own property, as he expends his substance idly and in a manner repugnant to the dictates of reason. Here he is placed under (legal) inhibition for his own advantage, because of the analogy between him and an infant.[1] However, Abu Hanifa is reported as disagreeing with this (in a lengthy and tortuous argument of the kind beloved by lawyers throughout history), on the grounds that "..if the *safiyah* were subject to inhibition, he would be excluded from humanity and connected with brute beasts, an exclusion still more injurious to him than any extravagance of which he could be guilty." Abu Hanifa argues that the property of the *safiyah* be withheld from him until he reaches the age of 25, and then be delivered to him regardless of his capacity for discretion, since "Withholding property from the person in question is intended to operate merely as instruction, or as a species of discipline; and it is most probable that a person attaining the age mentioned, will not be disposed to receive instruction...." Two disciples of Abu Hanifa, however, argue the other point of view, namely that "...his property must not be delivered to him until such time as his discretion be fully known; and that in the interim all acts performed by him are invalid; for as mental imbecility is the occasion of the

obstacle to his power of action, it follows that the obstacle continues as long as the occasion of it remains; - as is the case of the infant, who remains subject to inhibition during the continuance of his infancy.

The debate is not rendered any clearer by the absence of definitions of the relevant Arabic words. The *Majallah al-Akhan-i-Adliya*, a codification of Hanafi *fiqh*, gives the following: "*Matuh* is the person being so deranged in mind that his understanding is small, his speech confused and his plan of action bad. A *safih (safiyah)* is a person who wastes and destroys his property uselessly, by throwing it away and by scattering and squandering it in his expenses. Those persons who come to be deceived in business, in not knowing the ways of work and profit by reason of their being very stupid and simple, are also considered *safih*."[2]

Clearly in any language the terms for someone of small and slow wit are likely to be sometimes a factual description and elsewhere a term of abuse, which it becomes difficult to distinguish centuries later. However, Abdur Rahim states that "The jurists are all agreed on the authority of a text in the Qur'an that if a person on reaching the age of majority is found to be of weak intellect, his property should not be made over to him until he has developed sufficient judgement and discretion and this will be presumed at the age of twenty five. Further a person of weak intellect even after that age is to be placed under inhibition by order of the Court, as far as making of contracts, and dispositions is concerned, in order as much to protect his own interests as those of the public. Abu Hanifa however says that such interdiction is lawful but not obligatory."[3] (The age of puberty was taken as the usual age of majority, assumed to be 12 years of age for males and 9 years for females, with a maximum of 15 years in either case, regardless of external signs of puberty).

Given this level of debate on mental disability in the 8th and 9th centuries A.D., it is not surprising that there was a good deal of psychiatric activity in the Muslim world of that time, and in subsequent centuries until the decline of Arab power. It is chronicled by Dr Taha Baasher who says that there are more than 25 Arabic terms to denote a 'mad' person. Baasher describes the work of the 10th century Arab scholar Nasaboury, who classified mental illness into five categories including that of the *akhraj*, a group with defective judgement, incompetence in management and disturbance of temperament, including the mentally defective (*khabal*). he also gives details of the extensive hospitalisation and sensitive therapeutic measures provided in various Arab countries during eight centuries.[4]

1. See *The Hedaya (or Guide): A Commentary on the Mussulman Laws;* translated by Ch. Hamilton, Lahore: Premier Book House, 1963 (reprint).
2. See *Majallah al-Ahkam-i-Adliya*, translated by C.R. Tyser and others, Lahore: All Pakistan Legal Decisions, 1901.
3. See Abdur Rahim, *Muhammadan Jurisprudence*, Lahore: Indus Publishers, 1968 (reprint).
4. See Dr Baasher in *The World History of Psychiatry*, New York: Brunner-Mazel Inc., 1975. *(See also M.W.Dols (1987) Insanity and its treatment in Islamic society. Medical History, 31: 1-14.)*

The following story, written in 1982, appeared in Mensa Journal International No.275, April 1984, p.2; and Western Pacific Rehabilitation Bulletin Vol.1 No.1, June 1986. Children's brains are still being measured, but with more caution now in the interpretation of results and recommendations for action.

MEASURE FOR MEASURE: VILLAGE MOTHER VERSUS INTERNATIONAL PSYCHOLOGIST

The international psychologist is an orderly scientific person wearing a white coat and measuring children's brains. The village mother, as everybody knows, is dull, deprived, non-literate, messy and of very small brain. So if you are a slow-learning child, it is more comfortable to be measured by a village mother than by an international psychologist.

The psychologist sends his research team to the village and asks mothers: "Did your child do this or that at the same age as other children?" The village mothers answer "Yes". They know that when White Coats come from the city, it's best to say "Yes" to whatever funny things they ask. More White Coats arrive and ask "Does your child do this or that as fast as other children of the same age?" The village mothers answer "Yes". Perhaps if they were to answer "No", the White Coats might take their child away.

What silly questions the White Coats ask anyway! How do you know the age of your child, except by what he is able to do? If he has learnt to run around, then he is about two years old. If he can talk properly and tell a story, he must be about four years old. If he goes to school, it is a sure proof that he has reached the age of six. But if he cannot dress himself, then perhaps he is only three or four years old, even if he has grown quite big.

The people in white coats always seek the year, the month and even the day of your child's birth. Who should know such a thing? It is past and gone - it will not come again. Surely they must be seeking some bad omen from that day and month! They will search and find the star beneath which your child was born, and so gain magic power over the child. But they will have to search somewhere else, for you cannot tell them the year, the month and the day. If they suggest one to you, better to say "Yes, that was it". The funny people in white coats nod and grimace to one another, they make marks on white paper.

Where the White Coats come from, they catch children and measure them from the day they are born. They have clever measures and any child who is not fast enough gets found out. They take those children away from their families, far from their mother and father, far from their brothers and sisters, their grandparents, their uncles and their aunts. Those children are never seen again: torn from their home and family, their souls fly away. Only their bodies are left, rotting like bad vegetables in a big house in the city. They were measured and found out.

We do not measure children so in our village. When a child is ready to walk, he will walk. When a child has reached the point of telling what he saw in the field, he tells it. When he can cast a stone to drive the birds from the crops, he casts it. We say "He is growing up. Soon he will be a man."

It is not our custom to separate a child from his family and drive him out and punish him. But we have heard that it is the religion of the White Coats. It is said that their god measures everybody and accepts only few into his house. Most are driven out. Perhaps that is why the White Coats spend their time measuring and measuring.

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PAST & FUTURE MENTAL HANDICAP STUDIES

Towards a Bibliography of M.H. Studies

Formal studies of some aspects of mental handicap in Pakistan have been made since the 1960s, and maybe earlier (cf. reports by Johnston, 1886 and Ewens, 1903 on the shrine of Dauley Shah at Gujrat, where microcephalic children are to be found). Bushra et al reported (1975) that "A total of 3,7860 mentally retarded cases were examined in the Department of Neuro-Psychiatry, Jinnah Postgraduate Medical Centre, during the period of 10 years", which is more than double the total reported from the same centre by Beg et al in 1971. Some studies have been published in journals of general medicine, psychiatry, pharmacology, pediatrics, psychology, education, sociology and social work, also in magazines, bulletins, newsletters and medical or general newspapers. Some studies have been presented in conference papers, or as dissertations or theses for University degrees, but have not otherwise been published. (The present review concerns only those items produced in English).

Given the range of possible outlets, many of which have a very limited circulation or are published abroad, and the weaknesses of libraries and information science in Pakistan, it is not surprising that no comprehensive bibliography has yet been produced of mental handicap studies and allied topics. To do so would be a useful exercise, much more so if it were to include brief summaries and annotation, to differentiate research having some solid content from studies that are little more than journalism.

Some partial bibliographical efforts have in fact been made. In 1988, the Pakistan Psychiatric Society published a short bibliography of works by Pakistani psychiatrists, compiled by Dr Imtiazul Haq, as part of a handbook entitled Psychiatry in Pakistan (pp.102-114). The PPS may be contacted via the Neuro-Psychiatry Department of Jinnah Postgraduate Medical Centre, Karachi. This bibliography is largely of psychiatric work, but contains some references to published papers on aspects of mental handicap (including epilepsy).

A reference list published in 1988 by the Division of Mental Health, World Health Organisation, Geneva, entitled International Reference List of Resource and Research Centres in the Field of Mental Retardation, lists (pp.33-35) three such centres in Pakistan:

a) Child and Family Psychiatry Unit, Dept of Pediatrics, Mayo Hospital, PO Box 621, Lahore.
b) Mental Health Centre, Mission Hospital Compound, Peshawar.
c) Dept of Neuropsychiatry, Jinnah Postgraduate Medical Centre, Karachi.

The first and third of these centres indicate that 'some 50' and '100+' papers have been published by their staff. Presumably these could be listed and made accessible, with a little effort. Those that have been formally published in reputable journals will also be listed in Index Medicus, Excerpta Medica, Social Sciences Citation Index, Psychological Abstracts, Resources in Education etc. The Mental Health Centre staff have also produced about 120 books and 'published papers' having direct or indirect relevance to mental handicap (depending on definitions of 'published' and 'paper'). Some of these are listed at the end of this appendix, pp.56-58.

Aspects of mental handicap were reviewed in the National Workshop on Community Mental Health Research, October 1989, at the Dept of Psychiatry, Rawalpindi Medical College, a WHO Collaborating Centre for Mental Health Research & Training. This centre has been developing rural mental health care,

and publishing reports and material. Mental handicap is only one of many mental disabilities encountered, but the work is relevant to any attempt to extend services beyond the cities. The research workshop identified many topics needing attention. It is unclear how many have seriously been taken up.

Two bibliographies extending to 1986 are worth mentioning, on the negative side. They cover anthropology theses and 'social research', and indicate that mental handicap has not benefitted from research under these headings:

Bhatti, K.M. (1986) Annotated Bibliography of Social Research in Pakistan. Peshawar: Pakistan Academy for Rural Development. (*540 annotations in 141pp. Stronger on rural development and administration*).

Javed, M. & Asghar, M. (1988) Research Studies at Quaid-i-Azam University Islamabad: Theses submitted to the University up to 1986. Lahore: Al-Waqar.

The normal child and child-rearing methods, which are pertinent to the management and education of mentally handicapped children, are also scantily treated in the above bibliographies. However,the National Institute of Psychology, Islamabad, has conducted and published some studies of child development, learning processes and child psychology, and for several years has accumulated a computerised citations database of research in psychology (and allied fields), which covers many aspects of mental handicap and offers search facilities. A round-up of work on children, to 1986, is given in:

Pervez, Seema (Ed) (1989) The Pakistani Child: Educational & Psychological Research. Islamabad: National Institute of Psychology.

However Pervaiz Naeem Tariq, in a chapter in the latter work, notes that most of the studies on children and child-rearing were conducted by "naive researchers mostly university students", who are expected to do research only to get a feel of what research is.

The Information Office, UNICEF, PO Box 1063, Islamabad, has on at least one occasion sent out a nationwide appeal, to try to collect published material relevant to children with disabilities, and has also accumulated some press cuttings of relevance, over several years.

Issues of Method

'Pure' medical research on pathology, biochemistry, neurology and pharmacology for mental handicap and allied conditions is already an international exercise driven by its own publications and rules. Pakistani doctors and scientists involved in these fields need no instruction from here. Aetiology, genetics and epidemiology are a little more locally governed, in so far as they have, or result in, sociological links. On the other hand, research on assessment, linked to management, brings in the full range of educational, psychological and sociological factors, and here the 'rules' are a good deal more obscure.

A much-debated topic in international social science during the 1980s has been the relevance or irrelevance of 'Western' interests and methodology to social science research in non-Western countries. Clearly there should be an 'indigenisation' of social science research. Current Western knowledge and theories may be poor aids, or even obstacles to this process. There does not yet seem to be much progress in devising Asia-friendly paradigms, or Pakistan-relevant methodology. Many senior people now teaching social science in the developing (or newly industrialising or urbanising) countries did their post-graduate work in one of only five or six Western countries, mostly in English medium. When they were doing those studies, from 20 to 40 years ago, there was less concern about the 'relevance' of such work. It was believed that the then-current Western approaches to the social sciences were simply the best

available, and the graduates would return to their countries and build new departments of social science, which would apply the best Western theories and knowledge to the manifold problems of the Third World.

Since setting out to do so, their contacts with the Western 'wave-front' of research has largely been through international journals, almost all of which are in English, are edited and produced in the West, and treat mainly of Western concerns. Thus, although many of these senior figures are uneasily aware that their own studies did not prove very relevant to the real-life social problems of their countries, it may have been extremely difficult for them to cast off the bonds of 'intellectual colonialism'.

The Western social sciences since the 1960s have continued battling for recognition as 'science' while at the same time they have attempted to become more realistically involved with the messy, unsystematic, often unpredictable lives of ordinary human beings (among whom the scientists have also recognised themselves). There has been a growing awareness (not without opposition) that human individuals cannot usefully be studied as one studies plants or microbes; and that the statistical handling of the behaviour of human masses is less certain than the equivalent dealing with masses of gas molecules. A consequence of this has been that, while one can teach much the same methods for agricultural botany or laboratory physics anywhere in the world, it is not nearly so clear that the same approaches can be used in the social sciences.

Most Western countries have detailed large-scale maps of the whole country, showing virtually every dwelling, continually updated and publicly accessible. There has been for many years a tightly controlled and universally extended system of registering births, marriages and deaths, with cause of death. There are regular censuses, with data computerised, deeply analysed and published. There are detailed, publicly accessible lists of voter registration and other forms of Government registration, identity cards, national insurance numbers etc. There is massive, publicly accessible, data in the public and university libraries. These all provide baselines which social scientists can stand on with some (though by no means complete) confidence, and can involve in their investigations. Many of these baselines do not exist in countries of Asia, or exist with minimal public access and with far greater doubts about accuracy.

Furthermore, people's attitudes and habituation towards giving personal information to investigators and getting information from official sources, the 'distance' between Government and the individual, the individual's consciousness of his civil rights, the level of literacy and with it the objectifying of 'known facts', are all substantially different in countries such as UK and USA as compared with Pakistan and India. In some respects, far more will be known by community leaders about the details and personal lives of residents of a village or *mohalla* in Pakistan, than would be known by community leaders or neighbours or even close relatives of people living on a street in UK. But this information may not be accessible to any outsider, least of all to the Government or to social researchers. (Even the UK 1991 Population Census has admitted to 'losing' around one million people who intend to avoid having to pay an unpopular local tax!)

These differences and difficulties, however, must not be allowed to paralyse social research in Pakistan. In whichever country or culture, people who are faced by problems, or who have a little more curiosity than their neighbour, ask themselves questions such as Why?, Who?, How Many? When?, By What Means?, and make their observations, compare notes with others, draw conclusions, make

some mistakes, learn from the mistakes, modify their views in the light of further experience, and so on. The communication of these views, with supporting evidence, is the beginning of community-based science. To be sure, not every rural town will produce a Nobel Prize winner like Pakistan's Abdus Salam, or even a college lecturer. But every existing service centre or organisation for mental handicap in Pakistan is capable, at the very least, of creating and communicating some knowledge and producing some worthwhile record of observations and evidence (cf. studies reviewed in Miles, 1991a).

Future Studies

Ideally, in view of the points discussed above, the choice of topics should be driven by real situations and problems. Methods should be appropriate to the resources and understanding of those who will study. This may seem obvious, but in practice there have been many studies where the topic has been chosen by Westerners (looking for local partners to do the donkey work) and where the methodology is more rigorous than can be sustained in field practice, given the number of imponderables and confounders.

Many more studies are poorly planned in view of available resources, particularly of time and reporting. Masses of data are gathered but nobody has the time to collate and analyse it, nor to write the report and make sure it is circulated. Some studies are never written up at all. For others, an unsatisfactory report is fudged up several years later when the writer is preoccupied with other work. The time and energy resources used in data gathering are thus often virtually wasted. A more modest target of data would have left resources available for completing and reporting the study within a reasonable time period.

Mental handicap has implications for, and connections with, many aspects of human studies, so it is not intended to present here any global list of research priorities. The author believes it would be useful to know a great deal more about what actually happens in the daily lives of Pakistani families with mentally handicapped members - and this implies much greater knowledge of what happens in ordinary Pakistani families among people of normal abilitites, between parents, children, grandparents, brothers and sisters. Detailed domestic ethnography does not seem to have been carried out and published. If this is in fact so, there may be compelling social reasons for it, such as the sense of family privacy and the prevailing concepts of 'family', which may render analysis very difficult. However, if we do not build up a clearer picture of what actually happens inside families, then our efforts to help families manage the problems of mental handicap will be groping in the dark.

Allied to this, are questions of how knowledge is created or acquired, how disseminated and how modified, in Pakistan. Appendix IV discusses 'Information Based' approaches to rehabilitation, which offer prospects for millions of people to acquire and utilise knowledge at present stored in a few urban centres and in the heads of a few experienced professionals. These approaches will require on-going studies of information use, dissemination and feedback. It is quite feasible in Pakistan, with existing resources. It is a matter of motivation and choice. Ultimately, it is for Pakistanis to decide how their society is going to function, how resources will be allocated, how the best of available knowledge and practice can be made available to those who need it.

Published work by Mental Health Centre staff, relevant to Mental Handicap and Service Development. (# indicates surveys and ethnographic reporting).

CALEB, OLIVER C. (1986) (Urdu) *Helping Mentally Retarded People*. Peshawar: Mental Health Centre. (64pp).

CURRER, A.R.S. (1978) Report on the Community Mental Health Scheme (1976-1977). Peshawar: Mental Health Centre. (*Revised version expected, 1991, Currer, Alan & Currer, Caroline*).

CURRER, CAROLINE (1983) Pathan Mothers in Bradford. Some facts about their everyday lives; and some views concerning having a baby; rearing children; health and illness, happiness and sadness and health services. Coventry: Dept of Sociology, University of Warwick.

MILES, C. & MENTAL HEALTH CENTRE STAFF (1983, revised 1985 & 1990) (Urdu) Child Development Observation Checklist. Peshawar: Mental Health Centre.

MILES, CHRISTINE (1986; Rev.Edn.1991) Special Education for Mentally Handicapped Pupils: A teaching manual. Peshawar: Mental Health Centre & Palo Alto: Hesperian Foundation. *Available in English (revised, 277pp.), Urdu (tr. Razia Jaffer, revised 348pp.), Spanish, Marathi. In progress in Sinhala, Portuguese, French.*

MILES, CHRISTINE (*accepted for publ.*) Mobilising skills for special education in Pakistan: a personal cross-cultural experience. International Journal of Special Education.

MILES, M. (1979) Mentally Handicapped Children in Peshawar. Peshawar: Mental Health Centre. (*Digest publ. in Indian J. Mental Retardation 12 (1/2) 71-77; and Medical News Fortnightly (Karachi) 15 Nov.1978, pp.3,6).*

MILES, M. (1980a) Counselling parents of a mentally retarded child. J. Rehabilitation in Asia, 20 (April) 32-37.

MILES, M. (1980b) A school on the North West Frontier. British J. Special Education 7 (2) 32-33.

MILES, M. (1981a) Handicapped Children & Their Needs in the North West Frontier Province of Pakistan. Peshawar: Mental Health Centre. (30pp).

MILES, M. (1981b) Development of facilities for the mentally handicapped in the Republic of Ruritania over 50 years. Newsletter of the Federation of the Mentally Retarded (India), 7 (3). (Also Western Pacific Rehabilitation Bulletin 1 (3) p.9, 1986).

MILES, M. (1981c) Notes on a handicap strategy for Pakistan. J. Rehab. in Asia 21 (3) 34-39.

MILES, M. (1981d) Some historical notes on religions, ideologies and the handicapped. Al Mushir 23 (4) 125-134. (Christian Study Centre, Murree Rd, Rawalpindi).

MILES, M. (1982a) Integrated education for handicapped pupils: some practical drawbacks in developing countries. J. Rehabilitation in Asia 23 (April) 28-32.

MILES, M. (1982b) Why Asia rejects Western disability advice. International Rehabilitation Review 33 (4) 5. Also in Disabled People in International Development, 46-51. (1991). Winnipeg: COPOH.

MILES, M. (1982c) Enlisting community support for the mentally handicapped. Formative Years, Bulletin of Child Mental Health, Dec.1982, 3-9.

MILES, M. (1983a) Attitudes Towards Persons with Disabilities Following IYDP (1981). With suggestions for promoting positive changes. Peshawar: Mental Health Centre, for National Council of Social Welfare, Govt of Pakistan. *Survey of 286 urban and rural respondents, with literature review. Also available on ERIC ED 236 826 and Lib.Cong. P-E-84-931173.* (104pp.)

MILES, M. (1983b) Failure to persist with special education. J. Rehab. in Asia, 24 (3) 11-17.

MILES, M. (1984a) Sharing information for rehabilitation in the Third World. Development Communication Report 46, pp.1, 6,7. Also (1984) African Rehab. J. 1 (3) 10-12.

MILES, M. (1984b) Mental Handicap: Prospects for Pakistan. Paper presented at the Fifth International Psychiatric Conference, December 1984, Peshawar. (*Printed in the Conference Brochure*).

MILES, M. (1985a) Children with Disabilities in Ordinary Schools. An action study of non-designed educational integration in Pakistan. Peshawar: Mental Health Centre, for National Council of Social Welfare, Government of Pakistan, Islamabad. *Also available on ERIC ED 265 711.* (85pp).

MILES, M. (1985b) Where There Is No Rehab Plan. A critique of the WHO scheme for Community Based Rehabilitation, with suggestions for future directions. Peshawar: Mental Health Centre; & Palo Alto: Hesperian Foundation. (64pp).

MILES, M. (1985c) Problems of definition & categorisation of mental retardation in Pakistan. In Report on National Coordination Conference on Education of Mentally Handicapped Children, Islamabad, July 1985 pp.80-85. Islamabad: Directorate General of Special Education.

MILES, M. (1986a) Rehabilitation Broadcasts for Rural Areas Peshawar: Mental Health Centre; and Brussels: International League of Societies for Persons with Mental Handicap. (48pp).

MILES, M. (1986b) Misplanning for Disabilities in Asia. In K. Marfo et al. (Eds) Childhood Disability in Developing Countries, 101-128. New York: Praeger.

MILES, M. (1987a) Profound Mental Handicap: the Ultimate Challenge. Report on proceedings of an International Conference, Madrid, Nov. 1984. Brussels: International League of Societies for Persons with Mental Handicap. (84pp). *Available also in French, Arabic, Spanish.*

MILES, M. (1987b) Handicapped children in Pakistan: targeting information needs. Health Policy & Planning, 2 (4) 347-351.

MILES, M. (1987c) Vocational rehabilitation: realities for the rural Asian disabled person. African Rehabilitation J. 2 (No.10) 13-14. (Also The Pakistan Times, 15th April 1988).

MILES, M. (1987d) Community based rehabilitation for disabled persons. Postgraduate Doctor (Middle East), 10 (6) 380-383.

MILES, M. (1988) Special education in Pakistan: development issues International Journal of Special Education, 3 (1) 39-50.

MILES, M. (1989a) Information based rehabilitation for Third World disability. Social Science & Medicine, 28 (3) 207-210.

MILES, M. (1989b) Disability policies in Pakistan: Is anyone winning? International Journal of Special Education, 4 (1) 1-15. Also in The Pakistan Times, 6th & 13th May 1990, Mag.Sect.

MILES, M. (1989c) Rehabilitation development in South West Asia: conflicts and potentials. L. Barton (Ed), Disability & Dependency, 110-126. London: Falmer.

MILES, M. (1989d) Progress in disability awareness. UNESCO Special Education Bulletin for East & Southern Africa, 7 (1) 15-17.

MILES, M. (1990a) A resource centre developing information based rehabilitation. In M. Thorburn & K. Marfo (Eds.) Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research, pp.261-276. St John's, Canada: Project SEREDEC, Memorial University of Newfoundland.

MILES, M. (1990b) Special education in Pakistan. International J. Disability, Development & Education, 37 (2) 159-168.

MILES, M. (1990c) Disability & Afghan reconstruction. Disability, Handicap & Society, 5 (3) 157-167.

MILES, M. (1991a) Effective use of action-oriented studies in Pakistan. International Journal of Rehabilitation Research, 14 (1) 25-35.

MILES, M. (1991b) Mental Handicap Services: Development Trends in Pakistan. Peshawar: Mental Health Centre. (72pp).

MILES, M. & AURET, L. (1983) Mental handicap in Pakistan: development issues. Formative Years: Bulletin of Child Mental Health December 1983, 12-19. PO Box 621, Lahore.

MILES, M. & FRIZZELL, Y. (1990) Handling the cerebral palsied child: multi-level skills transfer in Pakistan. Physiotherapy, 76 (3), 183-186.

MILES, M. & MILES, C. (*in press*) Education and disability in cross-cultural perspective: Pakistan. In S. Peters (Ed) Education and Disability in Cross-Cultural Perspective. New York: Garland.

PETERS, H. & REHMAN, F. (1989) (*English & Urdu*) Community Directed Rehabilitation in the North West Frontier Province of Pakistan. Peshawar: Mental Health Centre. (48pp).

APPENDIX IV

PLANNING FOR MENTAL HANDICAP - AN INFORMATION BASED APPROACH

Limitations of Present Planning

Planning for mentally handicapped people, whether therapeutic, educational, social or vocational, tends to be driven by method, gadget, place, profession, budget and personal idiosyncracy. Specialists may focus too narrowly on issues such as special versus integrated classroom, norm- or criterion- referenced assessment, community- or institution- based services, central professional training or local incremental inservice updating. Parents may be preoccupied by the requirements of their own particular child. Meanwhile non-specialists, including health, education and welfare planners, are often still groping after basic concepts such as 'What is a mentally handicapped child? How should it be treated? What makes it go?'

These preoccupations do not lead to good plans. Planning requires a well-informed overview of the field, plus enough general public awareness to allow the implementation of plans. The mass media are sometimes asked to expand public awareness of disability issues and to inform all and sundry about rehabilitative programs. However, the organisation and implementation of mass information outreach rarely passes beyond tokenism.

Massive communication of information tends to be seen as a support rather than as a strategy in its own right. Also, media people are often poorly informed on mental handicap. They can lose their way in the rapid evolution of terminology, as rehabilitation administrators, professionals and consumers manoeuvre for ideological control of the field: from mental 'deficiency' to 'retardation' to 'handicap'; , from 'educational subnormality' to 'learning difficulty' to 'special needs'; from 'intellectual disadvantage' to 'intellectual challenge', and next year some new variations.

Rehabilitation and special education for mentally handicapped people may alternatively be viewed in information terms. To do so, avoids the limitations of each specialism and each individual. All are included, but none defines the field. To view the field in information terms, planners need to look closely at who has information, who collects it, who needs it, who distributes it, who monitors it, and how these processes can be improved and replicated widely.

But What Is This 'Information'?

'Information' can mean many things. A father with a cerebral palsied daughter may want 'information' about timings of wheelchair-accessible trains from Lahore to Karachi. That is *theoretical information* or KNOWLEDGE. To get this knowledge, the person must use some SKILLS or *applied information*, to understand a timetable or phone Railway Enquiries. Also, some preliminary *'attitudinal' information*, or CONCEPT, is needed for this person even to think of travelling by train with a wheelchair. Many people would never seek a timetable, because it would not occur to them that a wheelchair user should have the right to cross Pakistan by train. There is a concept involved in this information: here, the concept of accessibility. Without this concept, the attitude of the railway authorities will be that passengers should fit the train, not that the train should suit the passengers. Finally, for accessible trains to exist, more *applied information* in DESIGN must be used on the railway platform and carriages.

We can view information in terms of Concepts, Knowledge, Skills and Design. The modern 'information society' produces, circulates, applies and updates all these factors in vast quantities. It employs many people and modern technology

to make information accessible rapidly and widely, whether free, or at a price. The extent to which this is now happening, is accelerating, and potentially can happen worldwide, makes late 20th Century life qualitatively different from previous ages when there was comparatively little information, access and mass communication.

The main current rehabilitation strategies - Traditional, Institutional, Client/Family- and Community- Based, Resource Centre, Media-Based - each have some information content, varying in scope, transmission, accountability and accessibility. The following table sketches these factors comparatively:

INFORMATION CONTENT OF SOME REHABILITATION STRATEGIES

Strategy	Scope of Information	Transmission	Monitoring & Accountability	Accessibility
Traditional Rehab.	Limited but ecologically appropriate.	Handed down within families and localities.	Accountable for local successes or failures. Closed to wider scrutiny.	Only by meeting local healer. Costs are locally appropriate.
Institutional Rehab.	Cumulative & specialised. Not always appropriate.	Professional training and supervision.	Usually subject to some official system of inspection - (not always effective).	Often limited to urban areas. Cost and timings often inappropriate.
Client/Family or Community Based Rehab.	Varies with capacity of individual to grasp and use.	Individual to individual, with assorted back-up media.	Little monitoring in practice, due to wide scatter. Individual may complain of abuse.	At point of need, though back-up may be distant and costly.
Resource Centre Rehab.	Cumulative & specialised & progressively more relevant to clients.	Many levels of training, self-help & organised transmission.	Feedback from clients, professional users. Open to official use and scrutiny.	Principally urban, but aims for wider coverage and low cost.
Media Based Rehab.	Whatever can be effectively communicated in 2-dimension media.	All possible 2-dimension media.	Usual public media accountability. Some professional and client feedback.	Very wide access, usually at low cost.
Information Based Rehab.	Involves all the above strategies			

Consider the 'information content' of a traditional rural healer. Over many years, he has learnt, by watching and listening to his father and grandfather, the *concept* of healing, the *knowledge* of herbs, some *skills* of massage or counselling, the *design* of different medicines. He may teach these to his son and grandson. If not, the 'information' will die with him. People who need healing must go to the healer's house or send messengers. With a competent and compassionate healer, the system may deliver what people want. But if it works badly, there is often no alternative, no access to better information.

Contrast this with a rehabilitation manual, in a literate society. The manual discusses *concepts* of healing, adaptation and management, and sets out clearly the *knowledge* that can be applied in *skills* of therapy or self-therapy and in *design* of equipment or environment. This information accumulated in the author's personal experience and maybe professional training, and has been reviewed and supplemented by peers. Once formulated and written, it is

comparatively easy for ten thousand copies to be printed. They can be communicated by the existing worldwide mail system, direct to people who want the information or indirectly through bookshops, libraries, clubs, colleges.

Books make much information accessible, but may lack the 'human' dimension. That is good, in that books do not get tired, cannot dislike the reader, nor repeatedly demand fees. It is bad, in that books cannot 'care', cannot feel, cannot adapt to the unexpected. Books can provide concepts and knowledge, but can only suggest skills and design. They require the reader to make an effort and do what she reads about. They are effective only if she is literate, in the right language. This effectiveness can apply also to the reader's friends, neighbours, students etc, and with care can last for 30 years or more.

Compare this again with a 1990s multi-media self-training package, using video cassettes, booklets, interactive computer simulation disc and a pouchful of microfiches. These media can emulate three dimensions, can present more information, more powerfully, than a shelf of books and can adapt to different learning speeds and styles. A well-designed package can stimulate/communicate as much information as an average student would learn in 9 months at college.

Information Stores and Needs

Information and personal experience of mental handicap and of using rehabilitation services is stored informally with disabled people and their families and neighbourhood, and in some written and visual material. Information and experience of providing formal assessment, counselling and rehabilitation services rests with various professionals, and in written and visual format. Informal rehabilitation knowledge and skills are also widely dispersed in the community, e.g. in a family that has adapted its house for the needs of a hyperactive child; a *dai* who notices early signs of abnormality in the neonate; a carpenter who makes a standing frame for a child with cerebral palsy; a primary school teacher who detects hearing loss in several pupils each year and refers them for testing; a schoolgirl who makes shopping trips with a mildly retarded woman to help her with household management.

Information needs are very diverse: the elderly couple who hear that their grandchild has Down's Syndrome; the health assistant wanting to refer a baby with delayed milestones; the middle-aged man who must find some occupation for his mentally handicapped son; the students whose teacher is in hospital with severe brain damage after an accident; the parents who want to redesign a bathroom to admit their spastic daughter's wheelchair; the doctor needing a stock of pamphlets on epilepsy to give to families; the mother who suspects sexual interference by a cousin on her mentally handicapped son.

To meet the vast variety of information demands, and to effect the actual information transfer, at present involves many factors. In most countries, heavy constraints are experienced, e.g. professional jargon and concealment; high cost of consulting experts, when they are available; over-specialisation and segmentation by type of impairment; narrow dissemination and inappropriate orientation of family counselling material; compartmentalisation of health, education and social welfare fields; tendency of organisations either to gather or to distribute information, but seldom to combine both functions.

No human society yet has solved the problem of accessibility and active distribution of appropriate rehabilitative information; but with modern communications development, such a plan is technically quite feasible. It is feasible in many developing countries, given the high motivation of

information seekers and the indigenous tenacity in getting recalcitrant machines to work. In Pakistan, the present level of computerisation in WAPDA, T&T, Sui Gas and the Banks shows what can be done by big organisations, but micro-computers are also growing fast in smaller set-ups. By 2000 A.D., advanced technology should be available even in neglected fields such as disability. To begin, however, requires reconceptualisation of the field with information as the key feature, i.e. as Information Based Rehabilitation.

Potentially the benefits are many, and are low-cost. Concepts, knowledge, skills and design, for disability recognition, management and rehabilitation are mostly communicable in print, or by print augmented by audio-visual media, without substantial risks or loss of quality. Manuals, pamphlets, magazines, newspapers, film, radio scripts, video cassettes, can be multiplied many times and made widely accessible with much greater ease and lower cost than the multiplication of special teachers, physiotherapists, vocational instructors, community-based rehabilitation workers etc, sited in special schools, clinics, rehabilitation institutions, resource centres. This will not make skilled workers redundant! It should mean that they will no longer spend 80% of their time on repetitive information tasks that could be handled either by someone with much less training; or by self-instruction using a set of video cassettes and booklets. They should instead be able to spend more time applying their specialist skills and upgrading the level of available information media.

Dissemination by Existing Means

The information, knowledge and skills necessary to make an appreciable difference, and often a radical difference, to the lives of 95% of the mentally handicapped people in Pakistan and other countries, is at present available in a few places. The problem is to multiply it and distribute it to every corner. For example, if we print 10,000 pamphlets on dressing and toileting skills with the severely retarded child, there is little benefit if 9,500 remain in a cupboard being eaten by ants.

The mass media, by their very nature, achieve daily what the professionals and their programs find difficult to do even occasionally : they deliver information to the home. In the fast-growing, shifting, non-cohesive urban societies, the mass media may be the only reliable, on-going links between the individual and the wider community. This may be so also in the increasing number of rural communities where traditional values are crumbling. If our illustrated pamphlet appears as a full-page supplement in a national daily, it can reach 200,000 homes and maybe 600,000 potential readers. Among them, perhaps only 2,000 have a severely retarded child then, and another 1,000 have had in the past or will have soon. But the page is also read by a further 30,000 aunts, uncles, cousins, grandparents and neighbours who know a severely handicapped child. Of these, another 3,000 may cut out the page.

A further 15,000 teachers, nurses, social workers, priests and mullahs, health visitors read it and some of them decide that it might be useful in the future. Perhaps 500 copies are pinned up on health clinic walls or in doctors' waiting rooms, to be read by an unknown number of people over the next five years. If fifty of them write to the newspaper editor, asking for more such useful material, he may be willing to run a series. All the re-use and additional readers cost no more than the original paper and ink.

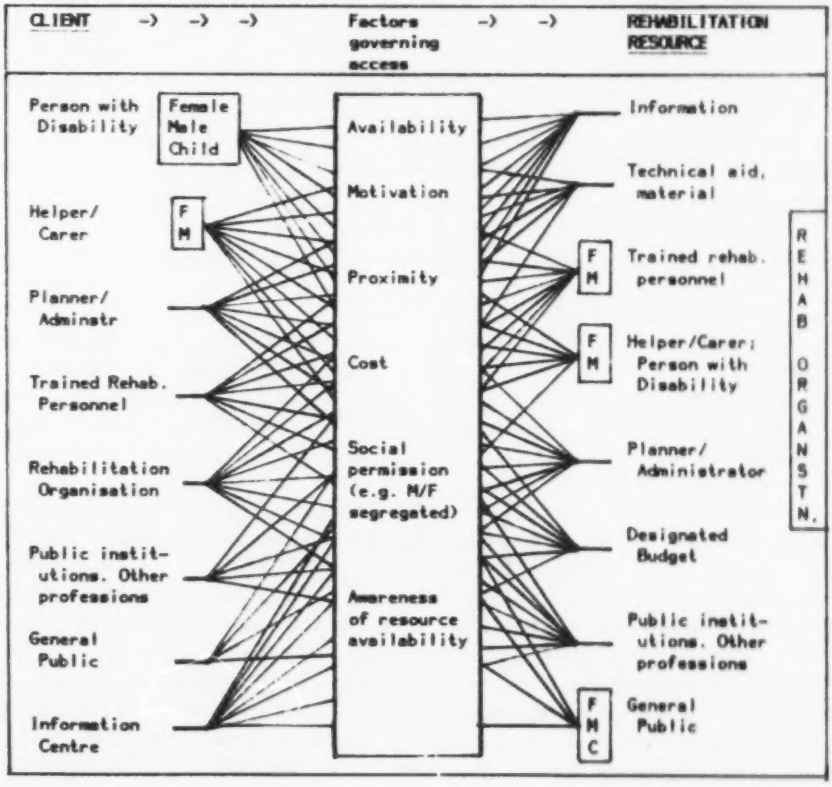
Target in Northern Pakistan

There is an 'information revolution' in rehabilitation and special education in a growing number of post-industrial societies. This goal is targeted also

in Pakistan, after several years of gathering experience with rehabilitation information and propaganda, at Peshawar and elsewhere. Other developing countries indicate that a similar process is in hand. Our experience includes preparing rehabilitation radio scripts, participation in filming documentaries and public service advertisements, and production of hard print media: books, pamphlets, magazine stories, newspaper articles and letters. Among these, the hard print media have been easier and cheaper to use since the production and distribution technology is widely available and familiar. The product is indefinitely available to the literate population, among whom it is reasonable to expect a higher proportion of trend setters and opinion leaders.

To start, an inventory was made of the availability of basic information at 4 levels on 8 categories of disability, appropriate for 4 broad categories of users, in Urdu and in English. Efforts are under way to fill the gaps, so that some culturally and linguistically appropriate printed information should be available at each level and for each category of disability. This is one part of a broad information strategy, shared with UNICEF and the Government of Pakistan, over the coming years. Lists have been compiled of publicly accessible and accountable distribution organisations, points or media, drawing on previous experience with health education campaigns, to disseminate information and *monitor feedback from consumers*. Feedback, which completes the information loop, is important for the establishment of on-going systems.

REHABILITATION INFORMATION/SKILLS NEED/ACCESS NETWORK



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Each network line in the above diagram represents hundreds of potential situations and many thousands of individual client-source linkages. Each major line needs to be considered carefully in terms of priorities and further analysed as a tool for planning. Some resources may conveniently be assembled in a rehabilitation organisation or institution, while others may better be integrated into normal health, education and welfare services. In any given city or rural area it should be possible to make an inventory of existing resources and estimate levels of access enjoyed by various sorts of client. From such an inventory, it becomes clearer which major resources are missing, how existing resources might more usefully be deployed and what should be the higher priority inputs.

It is important to note in the diagram that all the clients for rehabilitation skills or information may themselves also serve sometimes as resources. For example, the 'general public' acts as a resource wherever a disabled person appears in public and is treated normally and sensibly by those people who happen to meet him or her. Disabled people can be major rehabilitation resources when they counsel others or act as therapists, or help in the training of therapists. Public institutions or planners act as clients for rehabilitation information when, for example, a mosque, school or bank wishes to know how to provide wheelchair access, or a planner wants to know what sort of radio programs would interest blind adults. They can act as resources when, for example, a school provides integrated education; a bank provides a weekly reserved time when elderly, frail persons can do business in uncrowded and unhurried circumstances; a mosque provides a meeting room for a local association of disabled people; a planner allocates special resources for mothers bringing up disabled children.

This analytical approach attempts to bridge gaps of concept and knowledge between rehabilitation consultants, who know 'too much' about their speciality, and the generalist planner and decision-maker who needs to be able to get an estimate of the baseline and an overview of the main issues and factors. It assists planners or politicians to use their knowledge of the current general living conditions of their communities, and to see how an input of rehabilitation information/skills could have a useful impact.

What's Special about Information Based Rehab.?

What is new in the concept of Information Based Rehabilitation is the evaluation of strategies in terms of their information content, i.e. Concepts, Knowledge, Skills, Design, and the systematic planning of rehabilitation services, formal and informal, to maximise quality, quantity, dissemination and feedback of rehabilitation information systems and networks. This has several major advantages:

1) Instead of pitting strategies against one another, e.g. Institution Base versus Community Base, the information approach recognises the complementary nature of all the strategies.
2) One of the few clear advances of this century is the development of means to move information powerfully, rapidly and cheaply around the globe. The rehabilitation field can benefit greatly from this facility.
3) Information defies ordinary economics, in that it can be given away in any quantity without the giver having any less. In fact it multiplies in the process, because the giver receives feedback and so improves the quality of her information. (A feedback loop is needed also to monitor deterioration during transmission).

Comparing media

Print media have been the 'easy way to start' in Pakistan, but similar inventories are under consideration for non-print media. Radio and TV are of course accessible to a large non-literate population, insofar as receiving sets are available. But radio, TV and film production, however fashionable, is highly specialised, reliant on exotic equipment and subject to heavy central control, and thus seldom within direct reach of a non-government resource centre. The soft print media, combining visual impact with modest literacy demand - billboards, posters, photonovels, cartoon strip booklets - may have a more viable future for NGOs, together with videos.

Just as method and gadget sometimes dominate the rehabilitation field, so communication risks being over-influenced by "hardware primacy". Upcoming communications technology appearing intrinsically good, whether or not it is practical, affordable or effective, while established technology may be neglected or under-utilised, as often happens with radio. To avoid the hardware imperative, focus should start with software - the actual information content - and then discover not merely which medium to use, but how many media can be employed with mutually supportive and complementary effect. When it comes to advertising soap or fizzy drinks, marketing teams examine intensively the effectiveness of the various media. If they make mistakes, their product fails to sell, they go bankrupt and lose their jobs and investment. In the rehabilitation field our livelihood is less at risk, but there is no reason why we should not learn lessons from the business professionals.

Constraints

Information by itself is no panacea. Knowledge is 'structured information' and therapeutic skills are 'applied knowledge' - but the structuring and application may not be inherent in the raw information. Of course, any information medium gives some structuring, but clearly there is a need also for human mediation, whether by professionals or by consumer peers, and some reinforcement by a supportive network. Written material may need to be read aloud and acted out with non-literate populations.

Information, even of a technical nature, is seldom culturally neutral. Using mass media involves some risk of losing scientific attitude and accuracy along with some loss of respect for 'home-grown' user-friendly solutions. There is a risk of producing material that is both top-down in attitude and inaccurate in content. To reduce the risk, our rehabilitation broadcasts began formally with factual lectures but later emphasised the potential for low-cost rural rehabilitation, with more open-ended discussions between an interviewer and the parents of handicapped children or village disabled people.

Visual representations need careful field-testing and adaptation to convey the right meaning and exclude false meanings. There is some danger in using television where presentation does not lend itself to exact analysis, questioning, indication of discrepancies, reservations and explanation of the finer points. We look forward, nevertheless, to the day when every rehabilitation centre will have viewing facilities and a library of appropriate videos. Families, bringing their disabled child for assessment and counselling, gain nothing from sitting mutely on a bench, staring at the floor, while they wait for the specialist. They could instead be viewing a video about home management of a child like theirs. This would be a powerful basis for discussion when the specialist is ready for them.

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To find the right level of information for practical empowerment of mentally handicapped people and families in rural areas and urban slums is not easy. Professionals must stop thinking of rehabilitation as a package offered for hire, and offer instead an information process in which clients and communities are closely involved. Information supplied to professionals by consumers may help the needed attitude transformation. So may material depicting mentally handicapped persons and their families competently assisting themselves and one another.

Arranging feedback, monitoring accessibility and evaluating the whole system will require flexible, experimental studies and attitudes. Ensuring information access to specific socially disadvantaged groups, e.g. rural women and children, tribal and religious minorities, may represent as much of a challenge to local structures of power and privilege, as will the displacement of the professional from being the sole focus of the rehabilitation world.

Conclusion

Where professional skills and community resources are insufficient to meet the needs of more than a small proportion of the mentally handicapped population, and where economic and demographic factors remove all probability of reducing the gap in the foreseeable future, Information Based Rehabilitation offers an appropriate, low-cost reconceptualisation of the rehabilitation enterprise. Methodical information dissemination, feedback and evaluation, leading to on-going self-sustaining information systems, is an approach accessible to both Government and non-Government organisations. Despite many constraints, this may be the only strategy, for millions of disabled people, their families and nieghbourhood, that has any realistic likelihood both of benefitting them and of enabling them to help themselves.

A shorter version of this paper appeared in Parents Voice, Nov-Dec 1988. Versions of the diagrams appeared in the Journal of Visual Impairment & Blindness 84 (6), [1990]; and in Disability, Handicap & Society 5 (3), [1990].

REFERENCES

N.B. Where the reference is preceded by #, the work is not cited in the Survey Report, but is considered pertinent to matters under discussion. A few references that are given fully in the text, may not appear here.

ABDULLAH, TAHIRA (1981) The situation of disabled children in Pakistan. Islamabad: UNICEF (PO Box 1063).

AKBAR, RAJA M. (1989) A Survey of Special Education Facilities for the Handicapped Children in Pakistan. M.A. thesis, Dept of Educational Planning and Management, Allama Iqbal Open University, Islamabad.
Useful recent survey of institutional facilities and development. 102pp.

AHMED, QAZI IRSHAD (1988) Specialised services for the physically and mentally handicapped. In AHMED, S.H. (Ed.) Psychiatry in Pakistan pp.98-101. Karachi: Pakistan Psychiatric Society (Jinnah Postgraduate Medical Centre).

AHMED, S.H. (Ed.) (1988) Psychiatry in Pakistan Karachi: Pakistan Psychiatric Society (Jinnah Postgraduate Medical Centre).

ALI, ISAFNA JUZAR (1988) Child and adolescent psychiatry. In AHMED, S.H. (Ed.) Psychiatry in Pakistan pp.22-24. Karachi: Pakistan Psychiatric Society (Jinnah Postgraduate Medical Centre).

ANSARI, Z.A. (1989b) Indigenisation of Psychology in Pakistan. National Institute of Psychology Newsletter 8 (1) 4-6. (PO Box 1511, Islamabad).

BEG, RAIHANA; AHMED, AKHTAR; HASAN, ZAINAB; RIAZ, NUSRAT; HASAN, MEHER & HASAN, K. ZAKI (1971) Factors influencing the habilitation of the retardates. Journal of the Pakistan Medical Association, 20 (2) 52-61.

BOKHARI, S.A. (5 May 1989) Name of school. The Pakistan Times (Letters to the Editor).

BUDE, UDO (1990) Improving Primary School Teaching. An evaluation of the field-based teacher development programme in the Northern Areas of Pakistan. Dok 1597 C/a. Bonn: Deutsche Stiftung fur internationale Enwicklung.
Detailed report on many aspects of current normal teaching practice. 228pp.

BUSHRA, K., Hassan, K.Z., Jafarey, N.A. (1975) Effects if maternal age on mongolism. Journal of the Pakistan Medical Association, 25 (8) 195-197.

COUPE, J. (1987) Teaching Mentally Retarded Children. Report of a training workshop, Hyderabad, April 1987 Islamabad: Directrt. Gen. Special Education.

CURRER, A.R.S. (1978) Report on the Community Mental Health Scheme (1976-1977). Peshawar: Mental Health Centre. (*New edition expected 1991*).

EWENS, G.F.W. (1903) An account of a race of Idiots found in the Punjab, commonly known as "Shah Daula's Mice". Indian Medical Gazette 38: 330-334.

HAQ, IMTIAZUL (1988) Bibliography. In AHMED, S.H. (Ed.) Psychiatry in Pakistan pp.102-114. Karachi: Pakistan Psychiatric Society (J.P.M.C.)

HASAN, K. ZAKI (1971) Research in Mental Retardation. Karachi: Jinnah Postgraduate Medical Centre.

HASSAN, I.N. (1979) General features of psychopathology found amongst primary school children of federal area schools, Islamabad. In Proceedings of Fourth Session, Karachi 1979, pp.34-45. Islamabad: Pak.Psycholog.Assoc.(PO Box 1773).
Pilot study of 82 pupils with problems. Discusses need for guidance and counselling services in Pakistan.

* HENEVELD, WARD, & HASAN, PARWEEN (1989) Evaluation of Sind School Improvement Programme. Geneva: Aga Khan Foundation.

* INAYATULLAH (1989) Social sciences in Pakistan. An evaluation. International Social Science Journal, 41 (4) 617-633.

* ISRAR, MOHAMMAD (1985) Cognitive development of Pakistani primary school children: salient findings of a research project. In Z.A. Ansari et al (Eds.) New Directions in Pakistani Psychology, pp.67-74. Islamabad: Pakistan Psychological Association, PO Box 1773.
Summary of several years' work on Piagetian stages in Pakistani children.

JAFFER, RAFIQ (1981) Epidemiological survey of mental illness in Lahore city. (mimeo). Copies available from 14/E-iv Model Town Lahore.

* JAFFER, RAFIQ; WELLE-STRAND, ANNE & JAFFER, RAZIA (1990) Inside a Pakistani School. A study of primary schools in the Nathiagali and Mansehra regions of NWFP. Oslo: IMTEC, International Learning Cooperative (Rosenhof skole, Dynekilgt. 10, 0469 Oslo 5).
Frank report on the quality of teaching in typical rural schools. 56pp.

JAFFER, RAZIA & JAFFER, RAFIQ (1990) The WHO-CBR approach: programme or ideology - some lessons from the CBR experience in Punjab, Pakistan. In M. Thorburn & K. Marfo (Eds.) Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research, pp.277-292. St John's, Canada: Project SEREDEC, Memorial University of Newfoundland.

JOHNSTON, J. (1886) Ethnology of the chuas of Shawdow-la Temple, Goojrat, Punjab. Indian Medical Gazette, 1: 111-112.

KOHN, L.A. (1975) Goitre, Iodine and George W. Goler: the Rochester experiment. Bulletin of the History of Medicine 49: 389-399.

LARI, ZAHIDA S. (1988) The provision and development of special education in Pakistan. M.Ed. dissertation, Cardiff: University of Wales.

MALIK, HAFEEZ (1989) (Ed.) Sir Sayyid Ahmad Khan's Educational Philosophy: A Documentary Record. Islamabad, PO Box 1230: National Institute of Historical & Cultural Research.

MILES. *All references are to be found on pp. 56-58 of Appendix III.*

MUBBASHER M.H., MALIK S.K., ZAR J.R., WIG N.N. (1986) Community-based rural mental health care programme. EMR Health Services Journal 1, 14-20.

MULL, D.S., ANDERSON, J.W. & MULL, J.D. (1990) Cow dung, rock salt and medical innovation in the Hindu Kush of Pakistan: the cultural transformation of meonatal tetanus and iodine deficiency. Social Science & Medicine 30 (6) 675-691.

NASIR, SURRAIYA JABIN & ANSARI, ZAFAR AFAQ (1986) Guidance and Counselling Programme in Islamabad Schools. Islamabad: National Institute of Psychology, Quaid-i-Azam University.

* NATIONAL POLICY for the Education and Rehabilitation of the Disabled. (1988 Review). 1988. Islamabad: Ministry of Health, Special Education & Social Welfare, Directorate General of Special Education.
The current published policy of the Government of Pakistan on special education and ancilliary services. 30pp.

PERVEZ, SEEMA (1989) (ed) The Pakistani Child: Educational and Psychological Research. Islamabad: National Institute of Psychology.
Report of a national seminar held in 1986. Useful summaries of past and current research in this field.

* PRITCHARD, D.G. (1963) Education and the Handicapped 1760-1960. London: Routledge & Kegan Paul.

QUDDUS, NASEEM J. (1990) Problems of Education in Pakistan. Karachi: Royal Book Co.

* RAUF, A. (1975, 3rd Edn) Dynamic Educational Psychology. Lahore: Ferozons.

REPORT OF THE NATIONAL WORKSHOP on development and preparation of teaching/learning materials for mentally retarded children, March 1987, Islamabad, 1987. Islamabad: Directorate General of Special Education.

* REPORT OF THE SUB_GROUP on national programme for the promotion of mental health care in Pakistan. In AHMED, S.H. (Ed.) Psychiatry in Pakistan pp.80-93. Karachi: Pakistan Psychiatric Society (Jinnah Postgraduate Medical Centre).

SCHUCHARDT, E. (1980) The Social Integration of the Disabled Vol.1, Brunswick.

SPECIAL EDUCATION & SOCIAL WELFARE DIVISION (1990) Performance - 1989 Islamabad: Author.

TAREEN, K.I. (1983) Epidemiological Study of Childhood Disability. Survey / Study in Punjab (Pakistan). Interim Report. Lahore: UNICEF.

TAREEN, KHALIDA; BASHIR, ANJUM & NASAR, TANVEER (1984) A study of patterns of psychosocial disorders in children living in katchi abadis. Lahore, POB 621: Society for Mentally and Emotionally Handicapped Children.
Studies of children with psychiatric disorders, one clinic-based, one door-to-door in slum areas. 82pp.

WILLIS, THOMAS (1689) London Practice of Physick. Chapter 9, pp.497-502. Discussed further in CRANEFIELD, P. (1961) A 17th century view of mental deficiency. Bull. Hist. Medicine 35, 291-316.

WORLD HEALTH ORGANISATION (1988) International Reference List of Resource & Research Centres in the Field of Mental Retardation. Document MNH/MEP/88.4. Geneva: WHO Division of Mental Health.